

THE RELATIONSHIP BETWEEN PSYCHOSOCIAL FACTORS AND  
RESPONSE TO MEDICAL TREATMENT IN CHRONICALLY ILL ADOLESCENT PATIENTS

BY

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To  
Beverly  
and  
Molly

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THE RELATIONSHIP BETWEEN PSYCHOSOCIAL FACTORS AND  
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The present study was an attempt to examine the relationship between family and psychosocial factors and the quality of response of chronically ill adolescents to medical treatment. Previous research has generally supported the thesis that the development and course of physical illness is related to the following psychosocial factors: family functioning and structure, life stress, and social support. The primary purpose of the present study was to determine if, by assessing these three factors, it was possible to differentiate among chronically ill adolescents whose response to medical treatment was better than expected, those whose response was about as expected, and those whose response was worse than expected. The secondary purpose of this study was to determine if "worse response" adolescents were from dysfunctional families, and/or had

experienced high levels of stress, and if social support moderates the adverse effects life stress has on health.

Data was obtained from families each having an offspring (age 14-19) with one of the following four types of chronic disorders: pulmonary (N=21), gastroenterological (N=13), cancer (N=11), and juvenile rheumatoid arthritis (N=3). Parents from each family were administered the Family Adaptation and Cohesion Evaluation Scales (FACES), the Family Functioning Index (FFI), the Family APGAR (APGAR), the Schedule of Recent Events, and A Short Scale for the Evaluation of Social Support (ASSESS). Adolescent patients were administered FACES, APGAR, ASSESS, and the Life Events Record.

Results indicated that it was possible, using a discriminant analysis, to distinguish among adolescents in the sample from the three medical response groups. However, the jackknife validation procedure indicated that given a new sample population, the discriminant function derived from adolescents' data would identify members of the "as expected" response group, but would not differentiate members of the "worse" or "better" response groups. The validation procedure indicated that the discriminate functions derived from mothers' and fathers' data would not differentiate among any of the response groups.

The results did not support the hypotheses that medical response is associated with family functioning, that life stress is associated with poor medical response or that social support moderates the adverse effects stress has on health.



## CHAPTER I INTRODUCTION

Determining an accurate prognosis and providing optimal care for chronically ill children has long been a significant problem for the medical profession (Engel, 1962; Apley and MacKeith, 1973; Weakland, 1977). Recent studies conducted within the disciplines of epidemiology, psychology, sociology, and anthropology, as well as within the primary care disciplines in medicine, indicate that the family unit and the social environment play a significant role in both the onset of childhood disease and the response of the child to medical treatment (Cassel, 1976; Schmidt, 1978). However, these factors are often not taken into account in diagnosis and treatment (Jaffe, 1978; Schmidt, 1978). This is due, in part, to two factors: (a) the lack of a general framework for integrating existing medical knowledge with the new data on family and psychosocial factors in disease (Brody and Sobel, 1979), and, (b) the lack of a reliable, efficient, and integrated instrumentation for obtaining clinically relevant data on family and psychosocial factors (Pless and Satterwhite, 1975).

This study addresses these two problems in the following manner. First, this study presents evidence which demonstrates that General Systems Theory provides a framework for the comprehensive study of physical illness. Second, the relevant literature is reviewed and

critiqued from the perspective of General Systems Theory, and the significant psychosocial variables are identified. However, the basic purpose of this study is to determine the utility of a set of psychosocial assessment tools in differentiating among chronically ill adolescents patients whose response to medical treatment is better than expected, those whose response is about as expected, and those whose response is worse than expected.

### Rationale for the Study

Theories of disease have changed a great deal over the centuries and differ across cultures, being determined by prevailing views of human nature and the relationship of humankind to the cosmos (Dubos, 1965). At times emphasis has been placed on the whole person and her/his relationship to the physical, psychological, and social environment, while at others the focus has been on fragments of human nature, such as the mind or the component parts of the "body machine". Within the former perspective, disease is seen as a process which is inseparable from the person-environment interactive system. Within the latter ("ontological") view, disease is conceptualized as a specific entity which is essentially unrelated to a person's personality, bodily constitution, style of life, or environment (Dubos, 1965).

In prescientific medicine, the ontological doctrine took the form of demonological concepts with disease being regarded as the result of malevolent influences of taboo violations, sorcery, vengeful ghosts, hostile ancestors or animal spirits (Dubos, 1965).

In modern times, the ontological doctrine is still influential. Patients are prone to blame their illnesses on something they "caught", they ate, or that happened to them, or to account for their disease in terms of punishment. Further, the dominant theoretical model of modern scientific medicine, the biomedical model, is compatible with the ontological perspective. This model assumes that all aspects of human illness are the result of specifiable chemical and/or physical influences. Physicians find this model attractive, since it allows them to see the "cause" of all disease as something which can be changed physically, through surgery, or attacked and destroyed through chemical interventions (Brody and Sobel, 1979). However, within this perspective, consideration of the mind and the personal and psychosocial dimensions of illness are neglected or are changed into biochemical terms (Engel, 1977).

In the past two decades, the significance of personal and psychosocial factors in human health and disease has been clearly demonstrated. Considerable evidence has been accumulated which indicates that feelings of helplessness, hoplessness, and unresolved grief, generate or aggravate many illnesses (Engel, 1962; Schmale, 1958; Engel and Schmale, 1967; Wolff, 1968. Other research indicates that the stress involved in adjusting to a rapidly changing social environment may lead to or exacerbate a variety of physical disorders (Cohen, 1979; Rahe, 1972). Apley et al. (1977) estimates that psychosocial factors play a part in 45 per cent of all hospital admissions of children, and are the chief reason in another 15 per cent.

While research on the relationship between family interaction and illness is limited, this factor is considered by some medical researchers to be of preeminent importance in understanding the disease process (Meissner, 1966, 1974; Grolnick, 1972; Apley and MacKeith, 1973; Minuchin et al., 1975). According to Schmidt (1978) knowing what is "going on" in the family is as important as detailing the individual's symptoms. It is his belief that medical care could be both more humane and more effective, in terms of outcome and cost, if the providers of that care would consider the complex interactions that occur between the individual patient and her/his psychosocial environment. Further, a variety of physical disorders, including anorexia nervosa (Palazzoli, 1974; Minuchin et al., 1979), superlabile diabetes mellitis (Minuchin et al., 1979), intractable asthma (Liebman et al., 1974; White, 1979), and non-organic abdominal pain (White, 1979; Apley and Hale, 1973) have been successfully treated through family therapy.

While the research on the relationship between family functioning and the onset and course of disease has yielded promising results, it has failed to stimulate other investigators to enter the field. Weakland (1977), a prominent family systems theorist, has identified the area of physical illness and disease as a "neglected edge" of family systems research. Family Process, the flagship journal of family systems research, published only two articles related to physical illness in its first ten years (1965-1975) of existence. There have been only three empirical research studies published in this journal on this topic since Weakland's (1977) article suggesting the need for further research. The developments

in psychosocial and family systems research have also failed to influence established researchers in the medical field. The major medical journals concerned with psychosomatic medicine, the Journal of Psychosomatic Medicine, Psychosomatics and Psychosomatic Medicine, together contain only one article which adopts a family systems, rather than an individualistic or dyadic orientation to the psychological and psychosocial factors in disease.

Thus, while there is considerable evidence which indicates that family and other psychosocial factors play a significant role in the onset and course of physical illness, these factors have remained, on the whole, outside the main channels of medical thinking and experimentation.

#### Statement of the Problem

This study investigates the relationship between family interaction, life stress, and social support, and the response of chronically ill adolescents to standard medical treatment. More specifically, this study attempts to answer the following questions:

1. Is it possible to differentiate among adolescent patients whose response to medical treatment is better than expected, those whose response is about as expected, and those whose response is worse than expected by using data on family interaction, life change and social support.

2. Is the quality of response of chronically ill adolescents to medical treatment related to the quality of family interaction?

3. Is the quality of response of chronically ill adolescents to medical treatment related to the quantity of life stress experienced by the adolescent and/or other family members?

4. Is the quality of response of chronically ill adolescents to medical treatment related to the level of social support experienced by the child and/or other family members?

#### Definition of Terms

Adaptability: The ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress.

Adaptation: A dynamic balance between the processes of homeostasis and morphogenesis.

Causality, circular: The property of living systems in which information is processed. For example, information moves from A to B; from B' to C; from C' to D; from D' to A; from A' to B''; from B'' to C' etc. Each link is modified by the interaction, and the interaction involves a feedback loop (D' to A).

Causality, linear: A property of closed systems, in which a fixed quantity of energy is distributed through the system causing a fixed energy output. For example, energy moves along a chain from A to B; from B to C; and from C to D.

Closed system: a non-living system.

Cohesion: The emotional bonding family members have with one another and the degree of individual autonomy a person experiences in the family.

Disease: The failure of a living system to respond adaptively to environmental challenges.

Enmeshment: A property of family interaction in which there is a high degree of responsiveness to, involvement with, and interdependence on family relationships; a lack of personal privacy; poorly differentiated interpersonal perception, and "excessive"togetherness" and sharing.

Equifinality: The ability of living systems to reach the same final state from different initial conditions.

General Systems Theory: A paradigm developed specifically for the study of living organisms (systems).

Health: The ability of a system to respond adaptively to a wide variety of environmental challenges.

Hierarchical organization: General Systems Theory principle which holds that living systems are organized along ordered and highly structured lines, with clearly identifiable differential levels of complexity that relate in logical fashion one to another.

Homeostasis: The ability of living systems to maintain a dynamic steady state.

Isomorph: A principle of dynamic interaction or interrelationship which is characteristic of living systems in general.

Mathematico-reductionistic paradigm: The underlying assumptions of scientific method; the assumptions are that all phenomena can be (a) reduced into causal elements; (b) adequately described in terms of mathematical equations and laws; and (c) understood in terms of linear causality.

Morphogenesis: The ability of living systems to grow and change.

Omnipotentiality: The ability of living systems to reach different final states from the same initial conditions.

Open system: A living system.

Overprotectiveness: A property of family interaction in which there is a high degree of concern for family members' welfare,

Paradigm: The set underlying assumptions of a method of inquiry.

Rigidity: A property of family interaction in which there is a heavy commitment to maintaining the status quo.

System: A set of units or elements standing in some consistent relationship or interactional stance with each other.

Wholeness: General Systems Theory principle which holds that the behavior of a living system cannot be fully understood apart from its context or environment; nor can it be totally explained in terms of the behavior of its component parts.

#### Organization of the Remainder of the Study

The remainder of this study is organized into four chapters. The second chapter is a review of the related literature. Topics covered in this section include the basic principles of General Systems Theory and a review of research on the cause, course, and effects of physical illness based on the biomedical, psychosomatic, and family-systems models of disease. The third chapter presents the research methodology. The fourth chapter contains the results of the study. In the fifth chapter the study is summarized, the results and implications are discussed, and suggestions are made for further research.



## CHAPTER II REVIEW OF THE LITERATURE

### Introduction

Kuhn (1970), a leading authority on the history of science, states that all scientific inquiry is conducted within a specifiable scientific paradigm. This paradigm, or disciplinary matrix, is the set of underlying assumptions which determine how the phenomena in question are to be viewed and studied, what questions are asked and how they are posed, the possible methods by which the questions can be answered, the preferred models, analogies, and metaphors, and what will be accepted as an explanation. Kuhn also states that most researchers fail to identify the paradigm which underlies their inquiry.

The paradigm adopted by this investigator is General Systems Theory. In the first section of this review, the underlying assumptions and basic principles of General Systems Theory are outlined, and a model of disease, based on this paradigm, is presented. In the following sections, literature concerning the cause, course, and effects of physical illness based on the biomedical, psychosomatic, and family-systems models of disease is discussed. This literature is also critiqued from the perspective of General Systems Theory.

### General Systems Theory Paradigm

General Systems Theory was developed in the 1920s and 1930s as a reaction against the then dominant mathematico-reductionistic paradigm of scientific research. The basic assumptions of the mathematico-reductionistic paradigm are that all phenomena can be (a) reduced or broken down into essential isolatable causal chains, elements, or units, (b) adequately described in terms of mathematical equations, (c) adequately described in terms of precise mathematical laws, which hold invariably true under specifiable "standard conditions", and (d) understood in terms of linear causality (Bertalanffy, 1968; Steinglas, 1978; Wood, 1974). The method of inquiry employed in this paradigm is the analytic method. In simplest terms, the analytic method can be described as follows: the experimenter holds all factors constant but two, the independent variable (IV) and the dependent variable (DV), then systematically varies the IV and observes the effect of this systematic variation on the DV. By means of manipulations of this sort, the experimenter seeks to observe situations in a controlled manner, obtain clear, unambiguous results, and thereby determine the true nature of the phenomena under study (Giorgi, 1973).

Historically, this method has been most successfully employed by the natural or "hard" sciences (physics, chemistry, etc.) in which the phenomena under study can be carefully and closely controlled. In the life or "soft" sciences (psychology, sociology, biology, etc.) the phenomena under study do not lend themselves to rigorous control. Sophisticated research designs and statistical methods of data

analysis have therefore been developed to compensate for this lack of rigorous control (Giorgi, 1973).

Bertalanffy (1952, 1967, 1968, 1972) holds that the mathematical-reductionistic paradigm and the analytic method are inadequate for the study of living systems, since such systems are destroyed when broken down into component parts. Furthermore, he proposes a new model or paradigm for the study of organic, living systems; one which focuses on the general overriding principles (isomorphs) which characterize these systems. A detailed description of this new paradigm, known as General Systems Theory follows.

Within General Systems Theory, phenomena are conceptualized in terms of systems or "sets of units or elements standing in some consistent relationship or interactional stance with each other" (Bertalanffy, 1968, p. 38). All systems can be classified as either "open" or "closed".

#### Closed Systems

The behavior of all closed systems has the following characteristics: (a) they follow the Second Law of Thermodynamics (i.e., proceed toward a state of maximum entropy, a time independent state of equilibrium and disorder), (b) the final state is completely determined by its initial conditions, and any change in these conditions causes a totally predictable change in the end state, (c) all reactions are completely reversible (i.e., a reversal results in a return to the initial conditions), and (d) they can be completely isolated from the environment, and do not need to exchange energy (e.g., information, heat, etc.) with the environment in order to

exist and persist. Closed systems are in accordance with the basic assumptions of the mathematico-reductionistic paradigm, and are subject to study by means of the analytic method. All closed systems are, by definition, non-living.

### Open Systems

The behavior of open systems is fundamentally different from that of closed systems, and can be understood only in terms of the following principles of dynamic interaction and interrelationship (isomorphs).

1. Systems follow the principles of hierarchical organization and wholeness. Systems are organized, one to another, into a series of hierarchical levels. Every system is itself composed of component subsystems of smaller scale, and is, in turn, a component of a larger system. In closed systems, the behavior of suprasystems can be directly inferred from the combined behavior of subsystems. In open systems, each system within the hierarchy constitutes a functional whole and has unique properties. Thus, an open system cannot be adequately understood or totally explained in terms of the behavior of its component parts. The basic character of an open system transcends its components, and belongs to a higher order of abstraction. Similarly, no single element or group of elements within an open system can act independently.

2. Open systems can reach the same final state from different initial conditions. This is the principle of equifinality. In addition, different final states can be reached from the same initial conditions. This is the principle of omnipotentiality. From the

General Systems Theory perspective, the historical chain of events which may have preceded the present state of affairs is not seen as being especially important in understanding a phenomena. Rather, the focus is on mutual or circular causality, i.e., on critical elements and on the contemporary relationships between these elements.

3. Open systems are able to maintain a dynamic stability of subsystem properties or relationships within a fixed set of reference points. This steady state is maintained despite the continuous flow of both matter and energy through the system. As was demonstrated by Cannon (1939), organisms, in order to survive, maintain an internal dynamic steady state of critical biological functions, such as temperature, and electrolyte concentration. This process, which may involve the modification of the external, as well as the internal environment, is known as homeostasis. When this process involves a modification of the external environment, it is often referred to as assimilation (Piaget, 1971; Piaget and Inhelder, 1969; French, 1979).

4. Open systems are able to maintain sufficient closeness among subsystems and components to enable them to interact and to resist forces which could disrupt the system as a whole (i.e., homeostasis). This is the principle of cohesion.

5. Open systems have the ability to develop a higher order of complexity (i.e., to grow and change); to increase hierarchical organization and complexity of structure. This process, known as morphogenesis, involves the ability of a system to shift its fundamental reference points or parameters with respect to which an organism maintains its homeostatic balance (French, 1979). It is

analogous to the concept of accommodation (Piaget, 1971; Piaget and Inhelder, 1969).

6. Optimally functioning open systems achieve a state of adaptation, a dynamic balance between the processes of homeostasis and morphogenesis and are therefore capable of maintaining themselves within a wide range of environmental conditions. Open systems which follow the principles of homeostasis and morphogenesis are living systems.

#### Health and Disease

Based on the General Systems Theory model of living systems, Brody and Sobel (1979) propose that "health" is the "ability of a system (for example cell, organism, family, society) to respond adaptively to a wide variety of environmental challenges (for example, physical, chemical, infectious, psychological, social)" (p. 93). Thus, from the General Systems Theory perspective, health is a positive process, and is not merely the absence of the signs and symptoms of disease. This definition is not restricted to biological fitness or somatic well being, but rather, involves a consideration of the broader environmental, socio-cultural, and behavioral determinants of health. Further, health is seen as a dynamically changing state; encounters with environmental forces result in either a lower level of health, a restoration of equilibrium, or a growth-enhancing response.

Brody and Sobel (1979) propose that "disease" is the failure of a living system to respond adaptively to environmental challenges. Since all levels within a living system are interconnected, it is

expected, within the General Systems Theory paradigm, that a pathological disruption is not limited to one level of a system, but rather,

the disruption will tend to spread up and down in the hierarchy. For example, in diabetes, genetic and environmental factors interact to produce an initial disruption at the biochemical level that can lead to pathological changes in cellular function and a disruption of organ systems (for example, kidney and eye). Such changes are likely to disrupt the individual's behavior and may strain the family as well as produce a potential resource drain of the community. A disruption can also travel downward through the hierarchy, as when economic or natural disasters produce societal disruptions creating upheavals in community and family function that, in turn, precipitate a variety of psychosomatic or sociosomatic symptoms among individuals.

Therefore, from a systems view diseases are not regarded as discrete entities localized in one organ or tissue but as patterns of disruptions manifested at various levels of the system at various times. Patterns may differ in regard to where the disruption arises, which hierarchical levels are most affected, the type of environmental force that initiated the disturbance, and so on....(Brody and Sobel, 1979, p. 94)

From within the General Systems Theory paradigm, there are two complementary ways of intervening in a system's pathological process (Brody and Sobel, 1979). The first approach involves active invasive therapeutic interventions, either chemical or surgical. In systems terms, this approach involves a "disruption from the environment designed to oppose a specific disease-disruption, as when antibiotics are used to treat bacterial infections. The difference between a therapeutic disruption and a disease-producing disruption lies in the value of the ...(expected) outcome of each" (Sobel and Brody, 1979, p. 95).

The second therapeutic approach is aimed at strengthening the natural ability of an organism to adapt. In systems terms, this approach involves attempts to improve the information flow in the system in order to accommodate disruptions and facilitate the restoration of equilibrium. Since disease most often involves multiple levels, disrupting the person and the social group, multiple interventions directed at different levels can be therapeutic. Improving feedback and communication among family members, through family therapy, may stabilize the hierarchy at that level, rendering the family system more capable of handling challenges and resisting disruption, and potentially bringing about an improvement in the physical condition of a symptomatic family member. The work of Simonton and Simonton (1975) with cancer patients illustrates this approach. Standard biological therapies (radiotherapy, chemotherapy, and surgery) are combined with adjunctive support at the person level (various meditation and relaxation exercises) as well at the family level (group work and counseling). "While diseases may represent patterns of disruption affecting many hierarchical levels, a therapy aimed at just one level may be highly efficacious because it can affect other levels via the interconnected patterns of information flow" (Brody and Sobel, 1979, p. 96).

In the following three sections, literature concerning the cause, course, and effects of physical illness, as based on the biomedical, the psychosomatic, and the family systems models of disease, is presented and critiqued from the perspective of the General Systems Theory paradigm.



### The Biomedical Model

The biomedical model, which is based on the mathematical-reductionistic paradigm, holds that all disease processes can be fully accounted for in terms of deviations from the norm of a specifiable set of measurable biochemical variables (Weil, 1973; Engel, 1977). Within this model, disease is understood to be a discrete "thing" which is separable from its host and is capable of existing independently of it. This model proposes that all infectious illnesses are caused by bacteria and viruses, whose appearance correlates closely with other physical manifestations of illness (the "germ theory"). Further, it is held that the specific bacterial or viral cause of all illnesses can be identified through the analytic method. Since the biomedical model defines and identifies illness exclusively in terms of specific somatic and biochemical variables, it excludes social, psychological, and behavioral factors from the explanation of illness (Engel, 1977).

From the perspective of General Systems Theory, the biomedical model is conceptually inadequate, since it proposes a closed systems model to describe disease processes even though these processes behave like open, living systems. The open systems character of disease processes is illustrated by the fact that, rather than following the rules of simple linear causality, most pathological states, as they naturally occur, are the consequence of numerous factors acting simultaneously (Dubos, 1965). Further, in accordance with the open systems principle of omnipotentiality, noxious agents can express themselves in a great variety of different pathological

states. In accordance with the open systems principle of equifinality, different agents can elicit similar reactions. Finally, in accordance with the open systems principles of wholeness and hierarchical organization, a disease cannot be separated from its host; such a separation, itself, constitutes a pathological state (Dubos, 1965; Engel, 1977; Weil, 1973; Weiner, 1977; Brody and Sobel, 1979).

### The Psychosomatic Model

In this section, research conducted under the psychosomatic model of disease is discussed. The psychosomatic model of disease holds that mind and body are an inseparable and integrated whole, and that psychological and/or social, as well as biological factors, are significant in the development, course, and outcome of physical disorders (Lipowski, 1975). The studies are divided into two broad categories; those which focus on the identification of personality characteristics associated with specific illnesses or with illness in general, and those which correlate the incidents and course of disease with conditions of, and changes in, the social environment.

#### Personality Characteristics

The studies in this category are divided, according to their theoretical orientation, into the following two sections: psychodynamic and psychophysiological.

Psychodynamic theory. Exemplary of the psychodynamic approach is the work of Alexander (1950). This researcher sought to identify

predisposing factors involved in the initiation and maintenance of disease by analyzing clinical data produced in the course of psychoanalytic treatment and/or the study of patients with chronic organic ailments in which emotional conflict was thought to play an etiological role. Based on this data, Alexander proposed that the following three factors are involved in the onset of certain psychosomatic disorders: (a) a specific psychodynamic constellation or unconscious conflict (the "visceral neurosis"), (b) a specific "onset situation" which activated the unconscious conflict, and (c) a constitutional (genetic) vulnerability of a specific tissue or organ system, which was designated the "X" factor. Alexander held that disease developed only when all three factors were present and active in the appropriate combination. Alexander's observations of patients have been supported as valid descriptive findings by other investigators (Mirsky, 1958; Weiner, 1970; Dongier et al., 1956; Wallerstein et al., 1965). However, there is no clear, consistent, empirical evidence to support Alexander's contention that the psychodynamic factors which he identified play a primary causative role in the onset and course of the seven disorders which he investigated (Reiser, 1975; Weiner, 1977; Wittkower, 1974).

Psychophysiological theory. This approach to the study of somatic illness was developed by Wolff (1968) and his colleagues. These researchers focused on personality features and behaviors that were directly observable or measurable and that pertained primarily to conscious layers of a patient's personality and life experience. These researchers made psychological observations simultaneously with measurements of the physiological functioning of affected organ

systems. Based on their multi-method studies, Wolff proposed that illness is the consequence of a patient's perception of environmental situations as threatening to life itself or to emotional security. In the face of the perceived threat, the patient is hypothesized to protect and defend her/himself with an "organismic" response. The specific organ involved in the defensive response was said to be determined by the nature of the stress, and by the nature of the organ's functions.

Wolff proposed that the perception of threat is associated with an increase in risk for becoming ill with some kind of disease. Grace (1950) and Graham et al. (1962) expanded this formulation, proposing the "specificity of attitude" hypothesis. This hypothesis states that there is an association between a given disease and a specific attitude toward the life event(s) which first precipitates and later exacerbates the illness; that the attitude is different for each disease, and all persons with a given disease have the same attitude (Graham et al., 1962). Attitude is defined by these theorists in terms of how the person perceives her/his position in the situation, and what, if any action s/he wishes to take.

Summary. The linear cause and effect models proposed by the psychodynamic and psychophysiological theorists have been widely criticized as being conceptually inadequate and methodologically flawed (Reiser, 1975; Lipowski, 1977; Mirsky, 1957; Weiner, 1977; Engel, 1960). Because of a lack of predictor variables for disease, researchers were not able to select a relevant subject population prior to the onset of disease, and therefore were not able to conduct prospective studies. Without prospective studies, the role of

personality factors and associated physiological functioning in the etiology and course of disease cannot be demonstrated empirically (Weiner, 1977; Reiser, 1975).

Some studies conducted by these researchers demonstrated that patients with certain disorders resemble each other more than they resemble members of the population as a whole, or patients with other types of disorders. However, given even detailed accounts of a patient's personality, experts have not been able to predict with any degree of confidence and reliability, what disease, if any, a patient might have (Engel, 1955).

From the perspective of the General Systems Theory paradigm, the models proposed by the psychodynamic and psychophysiological theorists are conceptually inadequate since they clearly are not in accordance with the open systems principles of omnipotentiality, equifinality, hierarchical organization, and wholeness.

#### Psychosocial Factors

Research studies which examine the relationship between the psychosocial environment and the onset and course of illness can be divided into four broad categories: those which focus on specific traumatic life events and the quality of life, those which evaluate the quantity of life change, those which focus on social support, and those which look at family membership.

Quality of life. The most prominent theory in this category of psychosocial research is that of "object loss". This theory, which has been most clearly articulated by Engel and Schmale (Engel, 1968; Engel and Schmale, 1967; Schmale, 1972), holds that feelings of

bereavement, depression, helplessness, and hopelessness, which occur in persons who experience actual, threatened, or symbolic loss, are often associated with an attitude of "giving up". This attitude is hypothesized to be associated with a basic biological response state ("conservation withdrawal"), which acts in a non-specific manner to render an organism less resistive to existing somatic predispositions for illness or to external pathogenic factors.

Some researchers who have tested this theory of object loss have focused on feelings of hopelessness and helplessness. Representative of this line of research is the series of predictive studies (Schmale and Iker, 1966, 1971) which followed patients who were given diagnostic cone biopsies because of repeated evidence of suspicious cells, but who were asymptomatic for cervical cancer. Patients who reported real or apparent loss and/or feelings of hopelessness were found to be significantly more likely to contract cervical cancer.

Other researchers have focused on the impact of specific loss events. For example, in studies on the impact of the death of a spouse, it was found that widows retrospectively report a significant increase in minor physical illness, when compared with similar individuals who had not lost a spouse (Maddison and Viola, 1968; Parks et al., 1969; Parks and Brown, 1972). Other studies report an increase in mortality among widows and widowers in the six month period following the death of their spouse (Ekblom, 1963; Young et al., 1963; Jacobs and Ostfeld, 1977; Rowland, 1977).

Loss and separation have also been found to be associated with the onset of lung cancer (Kissen, 1967), rheumatoid arthritis (Engel,

1969), and ulcerative colitis (Engel, 1955). However, studies of American soldiers during World War II and concentration camp victims (Wolff, 1968), populations under military occupation (Malmaros, 1950), occupants of London during the "blitz" (Glover, 1940), and Hungarian refugees (Hinkle et al., 1958) report finding no significant relationship between loss or separation and morbidity or mortality. Thus, the findings of this line of research are inconclusive. This suggests that object loss in and of itself is neither a necessary nor a sufficient condition for illness onset; that loss may play a role in some cases of disease and death; and that the effects of loss may be moderated by other factors (Rowland, 1977; Cohen, 1979).

Quantity of life change. This theory holds that life change per se, regardless of the desirability of the change, is associated with illness onset and exacerbation. The most prominent life change model of disease is that formulated by Holmes and Rahe (1967a). This model proposes that life events cause an increase in physiological activity which, over time, has a wearing effect on the body, lowers body resistance, and enhances the probability that a disease will occur. Thus, a direct link between life change and illness onset is hypothesized.

In order to test their theory, Holmes and Rahe (1967a) first developed the Social Readjustment Rating Scale. Through this instrument, they determined the relative amount of psychological readjustment (intensity and length of time) necessary to adjust to each of 43 life events (e.g., divorce, death of spouse, change job). In their research on the connection between life stress and disease,

Holmes and Rahe used the Schedule of Recent Events (SRE) (Holmes and Rahe, 1967a), which contains the same 43 life events. On the SRE, subjects are asked to document the occurrence of the life event items over a specific period of time (usually 6 months). By adding the life change value of each life event, as determined through the Social Readjustment Rating Scale, a quantitative score, in life change units (LCU's), can be determined for each subject.

Research employing the SRE in the study of a variety of populations and diseases indicates that high life change scores (scores over 450) are associated with changes in health. Individuals with the highest scores have been found to demonstrate the most signs and symptoms, with even minor health changes being closely related to events requiring adaptive behavior (Petrich and Holmes, 1977). The following studies are representative of this line of research.

Jacobs and Charles (1980) in a study of children with leukemia, and Heisel (1972) in a study of children with juvenile rheumatoid arthritis, found that, for the year prior to disease onset, these chronically ill children had significantly higher LCU scores than physically healthy comparison groups. Prospective and retrospective controlled studies of deaths from myocardial infarction (heart attack) have shown that those patients who died had significantly higher LCU scores in the 6 months prior to infarction compared to those who survived (Rahe and Lind, 1971; Theorell and Rahe, 1972, 1975; Theorell et al., 1975). Stevenson, Nabseth, and Masuda (cited in Masuda and Holmes, 1978) found patients with duodenal ulcers had high LCU scores prior to needing surgery; and four years after surgery, patients with higher postoperative LCU scores had



significantly more residual symptoms than those with lower LCU scores. Allen (cited in Masuda and Holmes, 1978) in a study of patients with pulmonary tuberculosis, found that those patients suffering a relapse had significantly higher scores than those who did not suffer a relapse. One half of the relapse group had LCU scores over 450 (indicating a major life crisis). In a series of prospective studies of 5000 Navy personnel (Rahe, 1968, 1972, 1974; Rubin et al., 1969; Rahe et al., 1970), it was found that those men with the highest LCU scores for the 6 months preceding a sea cruise were found to seek significantly more medical care than those men with the lowest LCU scores.

When first proposed, the SRE and the life stress theory of disease gained great popularity among researchers in psychosomatics. Recently, however, the model has been criticized on methodological and theoretical grounds. On theoretical grounds, Cleary (1974) has questioned whether LCU values accurately represent the pathogenic significance of life events, and whether the effects are additive. Further, as different life events produce different physiological responses, Cleary questions the validity of a unidimensional life event scale. While Holmes and Rahe (1967b) suggest that all life events, whether positive or negative, increase the probability of disease, Vinokur and Selzer (1975) have found that the undesirable events of the SRE are the most strongly correlated with the onset of illness symptoms. Cohen (1979) notes that while significant results have often been found between LCU scores and illness onset, the magnitude of the relationship has often been small. In a Navy study (Rahe, 1974), for example, the correlation was low ( $r=0.12$ ). While

this is significant ( $p < .05$ ) in this large sample ( $N=5000$ ), the LCU scores accounted for less than 2% of the total variance. In some studies (Rahe et al., 1970; Rahe and Arthur, 1978), the correlation between illness and demographic and occupational factors was higher than that between illness and LCU scores.

Based on the fact that some people become ill or are hospitalized when no discernable changes in their lives have occurred, while others undergo many severely stressful events without developing any illness, Wershow and Reinhart (1974) conclude that the life stress model is incomplete. These authors suggest that coping factors, such as coping style and social support, play a significant role in moderating the effects of life stress.

In response to these criticisms, Rahe (1974) modified the original life change model, which posited a direct link between the quantity of life change events and the probability of disease onset. The new model proposes that there is a sequence of several moderating factors such as past experience, social support and other psychosocial defenses, coping style and illness behavior which act to increase or decrease the impact of a given life event.

Thus, based on the results of these studies and critiques, and in accordance with the revised life change model, life change events appear to play a role in the occurrence of many cases of disease. However, high life change is neither a necessary nor a sufficient condition for illness onset, and the effect of change may be modified by other factors (Rowland, 1977; Cobb, 1976; Dean and Lin, 1977; Murowski et al., 1978).

Social support. This model holds that a low level of social support is associated with a higher incidence of disease, while a high level of social support has a moderating effect on the impact of stressful life events and is associated with a lower incidence of disease.

A positive relationship between low levels of social support and increased somatic symptomology has been reported by several studies. In an epidemiological study of psychosomatic symptomology, Schwab et al. (1979) found that, compared to asymptomatic individuals, persons with psychosomatic complaints had more friends and relatives nearby, but were much less likely to utilize their support system by sharing problems or by asking for help in times of crisis. These researchers concluded that a relative lack of a meaningful support system is a common characteristic of the psychosomatically ill.

In a study of the relationship between social support and mortality, Berkman and Syme (1979) found that persons who lacked social and community ties, as measured by the Social Network Index (Berkman, 1977; see Appendix F), showed a higher rate of mortality than those with greater social ties. The age-adjusted relative risk for those most isolated compared to those with the most extensive ties was 2.3 for men ( $p < .001$ ) and 2.8 for women ( $p < .001$ ). A low level of social support has also been found to be associated with the incidence of specific disorders, such as tuberculosis (Jackson, 1954; Holmes, 1957), coronary heart disease in Chinese-Americans (Marmot and Syme, 1976), cardiovascular disease in Italian-Americans (Bruhn et al., 1969; Wolf, 1976), and ulcers in unemployed men (Gore, 1978).

Nuckolls et al. (1972) studied the relationship between

social stress, psychosocial assets (social support) and medical complications experienced during pregnancy. Data was obtained on a group of white married women of similar age and social class, all of whom were pregnant for the first time, and delivered at the same hospital. It was found that women with high life stress scores and low social support experienced significantly more complications than both women with high life stress and high social support, and women with low life stress scores (regardless of level of social support.)

In a related study, De Araujo et al. (1973) examined the association between psychosocial assets, life change, and dosage of adrenocorticosteroids required to control chronic intrinsic asthma. They found a negative rank order correlation between social support, as measured by the Berle Index (Berle et al., 1952), and steroid dosage ( $r = -.564$ ,  $p < .001$ ). There was no direct relationship between life stress scores, as measured by the SRE, and steroid dosage. However, when the life change and social assets scores were combined, it was found that patients with high social support scores invariably required smaller doses of steroids regardless of their LCU scores. Patients with low social support and high LCU scores required significantly higher doses than those patients with low social support and low LCU scores ( $p < .01$ ).

The results of these studies consistently support the hypothesis that social support acts as a buffer against, or moderator of, the adverse effects of stress. However, there is a methodological problem with this line of research; the conceptualization and measurement of social support used in these studies is not consistent. For example, the Berle Index, which was used in the De Araujo

et al. (1972) study, combines into a single score demographic and medical information, data on the patient's interpretation of family and interpersonal relationships, and the physician's judgment of the patient's past performance, personality structure, and attitudes toward illness. This measure has been criticized as being ambiguous, as measuring social status rather than interpersonal support, and as relying on the subjective judgments of the physician and patient (Murowski et al., 1978). TAPPS, the measure developed by Nuckolls et al. (1972) also combines information from several areas into a single score; this instrument tapped the areas of self-concept, attitude toward marriage and extended family, social resources, and attitudes toward the pregnancy.

Other instruments have focused on more discrete components of social support. The Social Network Index (Berkman, 1977), the instrument employed by Berkman and Syme (1979), assesses marital status, number of and frequency of contact with friends and relatives, and group membership and participation. Other researchers have developed measures of social support which assessed subjects' confidants and acquaintances (Miller, Ingham, and Davidson, 1976), availability of helpful others in coping with problems (Medalie and Goldbourt, 1976), values similarity (Brim, 1974), and degree of satisfaction with available support (Sarason et al., 1981).

Murowski et al. (1978), in a critical review of the measurement methods developed to evaluate social support, propose that researchers either have tended to use too broad a conceptualization of, or have focused on discrete components of social support. These researchers propose that the concept of social support, when used in

the study of illness, should be limited to the characteristics of interpersonal relationships, and should not include socio-economic factors or material assets per se. Further, they propose that the measurement of social support should include an inventory of those persons and institutions which provide interpersonal support, a measure of patterns of social affiliation, and an assessment of satisfaction with available support. They conclude that there is presently no adequate instrument to measure social support as it is related to disease etiology and coping with disease.

While the research on the relationship between social support and illness is limited by measurement and conceptual problems, the studies conducted to date strongly suggest that social support is protective of health. Further, while life stress appears to play a role in the development and course of some illness, the combination of factors of low social support and high life stress appear to be a better predictor of illness than either factor alone.

Family membership. This model holds that factors such as family stress, family adjustment, and interpersonal relationships within the family have a significant effect on disease course and onset.

In a study which focused on stress within the family, Meyer and Haggerty (1962) followed 100 members of 16 families for a year, periodically taking throat cultures for beta streptococci, and clinically evaluating illness. It was found that acute family crises, including accidents, illness or death, divorce, and job loss, were four times more common in the two-week period preceeding streptococcal infections and illness than in the two-week period following illness onset.

In an extensive seven year study of 223 adult medical and surgical patients, Duff and Hollingshead (1968) examined, among other things, the interrelations between disease onset and family adjustment. It was found that 47% of patients' illnesses were linked to unsatisfactory family relationships, and that a significant percentage of these patients came from severely maladjusted or moderately adjusted families. This study also found that two-thirds of the patient's physicians had no awareness of the connection between the patient's illness and the family situation. Apley (1959), Apley and MacKeith (1973), Kellner (1963), Peachey (1963), and Hopkins (1959) also report data which support the hypothesis that poor family adjustment and high family stress are significantly correlated with somatic symptomatology in family members.

Other researchers have focused on dyadic relationships within the family. Many of the early psychosomatic studies, as based on psychoanalytic theory, focused on the interaction of the mother-child dyad. Typical of this research is Forrer's (1960) case study in which it was proposed that an infant developed two different dermatological lesions in "psychosomatic compliance" with unconscious conflicts which the mother experienced in her own psycho-sexual development. This research has generally been refuted (Reiser, 1975; Lipowski, 1977) as being limited by its theoretical orientation, as ignoring the role of the father and other family members and as suffering from numerous methodological flaws.

More recently, researchers have focused on the relationship between physical illness and the dyadic relationship between husbands and wives. Typical of this line of research is the work of Cobb

et al. (1969). In his study of the intrafamilial transmission of rheumatoid arthritis, it was found that arthritic women were married to men with peptic ulcers with a frequency well above chance. Based on data from extensive interviews and medical histories, Cobb et al. proposed that the development and course of the two disorders was best understood as a part of the interpersonal relationship between the members of the couple. It was suggested that these couples develop a relationship because of the wife's tendency to be controlling and the husband's need to be controlled. When difficulties arise in the marriage, the resulting marital hostility contributes to rheumatoid arthritis in the wife via resentment and depression, and to the peptic ulcer in the husband via unmet needs for emotional support.

In a related study, Henker (1964) looked at recurrent psychosomatic illness in 37 couples treated in groups over a four year period. He found that exacerbation of symptoms coincided to a significant degree with periods of increased marital tension, and concluded that the onset of the somatic symptoms was caused by the tension within the marital dyad.

Summary. The psychosomatic models of disease, as elaborated by researchers focusing on personality characteristics, psychosocial variables, and family membership, have been criticized as being inadequate and highly inferential (Reiser, 1975; Weiner, 1977; Brody and Sobel, 1979; Minuchin et al., 1978). By employing the psychosomatic model, which holds that mind and body constitute a functional unity, these researchers sought an alternative to the restrictive biomedical model. However, these investigators utilized



the same model of linear causality and reductionistic methods of analysis that were used to develop and apply the germ theory. By adopting this methodological approach, they focused on a single factor or simple combination of factors, while ignoring dynamic interrelationships among personality, psychophysiological, and environmental variables, and proposed various linear models in which disease is understood to be contained within the individual (see Figure 1). Further, since these theorists lacked a common conceptual framework for psychological and physiological variables, they were able to demonstrate covariance between factors, but not the causality they sought to prove. While these studies show a correlation between illness and various life events, social support, personality, and family membership variables, these findings in and of themselves prove nothing about time sequence and causality, as understood in a linear sequence model (Reiser, 1975).

From the General Systems Theory perspective, the various psychosomatic models are conceptually inadequate, since they are not in accordance with the principles of wholeness, hierarchical organization, omnipotentiality, equifinality, and circular causality, as inherent in all open living systems. Grolnick (1972), in his systems oriented review of research on family-related factors of illness, proposes that it is simplistic to assume a linear sequence of events, such as marital tension-psychosomatic exacerbation or psychosomatic exacerbation-marital tension. According to Grolnick, "marital tension" is a system at a different and hierarchically higher level than "somatic processes"; the former is most appropriately understood

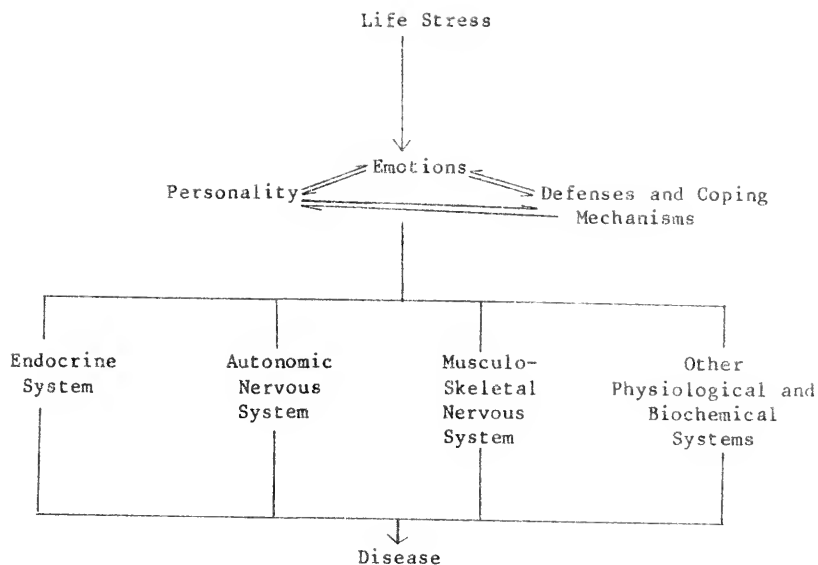


Figure 1.  
Linear Model of Disease  
(Minuchin et al., 1978)

to be the context within which the somatic symptoms occur rather than the direct cause of the symptoms.

### Family Systems Model

The family systems model of disease holds that the unit of analysis to which many disease processes can be most meaningfully related is the family system; and that the patient, through her/his symptoms, manifests pathology which is inherent in the family system. Thus, this model holds that disease does not originate or reside solely within the individual (Meissner, 1974; Brody and Sobel, 1979; Minuchin et al., 1978).

The most comprehensive research, using the family systems model of disease, has been conducted by Minuchin et al. (1978). This project involved the intensive study of two groups of families; one having children with chronic conditions under poor medical control, the second having children with chronic conditions under good control. In the first group were children with anorexia nervosa, intractable asthma, and superlabile diabetes. In the second group were normal diabetic children, and diabetic children whose illness was under good control but who had significant behavioral problems. Families were assessed by means of a family task interview, a structured interview, and long term family therapy. As part of the structured interview, a direct measure of the physiological effects of parental conflicts on a child's disease was made. The physiological measure used was blood concentration of free fatty acids (FFA). FFA serves as a measure of emotional arousal in the

general population (Bogdonoff and Nichols, 1964) and signals the advent of ketoacidosis (i.e., the state of poor control of diabetes) (Baker et al., 1974).

The results of this study indicate that the three types of "poor medical control" (PMC) families were similar to each other, and that they differed from the "good medical control" (GMC) families in several ways. Compared to the GMC families, the PMC families tended to be enmeshed, i.e., to be more responsive to, involved with, and interdependent on family relationships; to be more intrusive on other's communication; to have less differentiated perceptions of oneself and of other family members; and to have weak family subsystem boundaries. The PMC families tended to be more over-protective than the GMC families. The former displayed significantly more nurturant-protective and protectiveness-eliciting behaviors. PMC families were found to avoid and diffuse conflict more frequently. Families with normal diabetic children agreed and disagreed more, and considered more alternatives in completing the family tasks. The behavior problem families tended to diffuse conflict, but were able to express conflict more openly than the PMC families.

The results of the analysis of the physiological data showed significant results for the three diabetic groups only. The superlabile diabetic group was found to differ from the other two groups in two respects. First, the PMC children had a rise in FFA levels while viewing parental conflict. The other two groups showed a slight decline in FFA levels. Second, following the resolution of the parental conflict, the FFA levels in the superlabile group

remained elevated while the levels in the two control groups moved toward the baseline levels. While previous medical studies showed no intrinsic physiological differences among the children in these three groups, this experiment showed the superlabile group to have an exaggerated "turn on" and an impaired "turn off" physiological response to family conflict.

The physiological results also indicated that the PMC children played a role in maintaining family stability (homeostasis). FFA levels of the diabetic children were plotted against those of the parent whose arousal was highest during the interview. In the superlabile group, it was found that the parent showed a decrease in FFA level when the child was brought into the conflict situation. These changes in FFA levels were not found in the other two groups. Thus, while the superlabile child's stress was increased and her/his medical condition was exacerbated, the parent's stress was alleviated.

As part of this study, the symptoms of the PMC patients were treated by means of family therapy. All the children with superlabile diabetes had either a good or excellent level of control following therapy. Prior to therapy, all of the children with intractable asthma were on steroid therapy, were experiencing prolonged and severe asthma attacks, and were missing school for weeks at a time. Following therapy, 80% of the patients were having only occasional, mild attacks, were not on steroid therapy, and were not missing any school. The remaining cases showed moderate improvement. Of the anorectics who were treated through family

therapy, 88% were completely recovered, 6% were unimproved, and 6% relapsed after apparent successful treatment.

Based on this multi-variable multi-method experiment, Minuchin et al. (1979) proposed the following model of psychosomatic illness in children (see Figure 2). The symptomatic child is physiologically vulnerable, i.e., a specific organic dysfunction in present. The family has four organization or functional characteristics: enmeshment, overprotectiveness, a lack of conflict resolution, and rigidity. The symptomatic child plays an important role in the family's pattern of conflict avoidance, and this role is an important source of reinforcement for the child's symptoms.

In contrast to the models of disease previously discussed, which hypothesize that specific disease symptoms are related to a given family constellation or a simple etiological factor, this model posits that there are general types of family processes which encourage somatization and other dysfunctions, and that there are a cluster of related, interactive factors involved in the disease process. Causality in this model is circular: certain types of family organizations are related to the development and maintenance of somatic symptoms in children, and the child's somatic symptoms play a major role in maintaining the stability of the family's interaction and organization.

This open system model of illness, as proposed by Minuchin et al., is supported by the findings of several other studies. For example, Nye (1957) found that students from broken homes had fewer psychosomatic symptoms than did students from unhappy but unbroken homes. Nye interpreted this data as supporting the hypothesis that

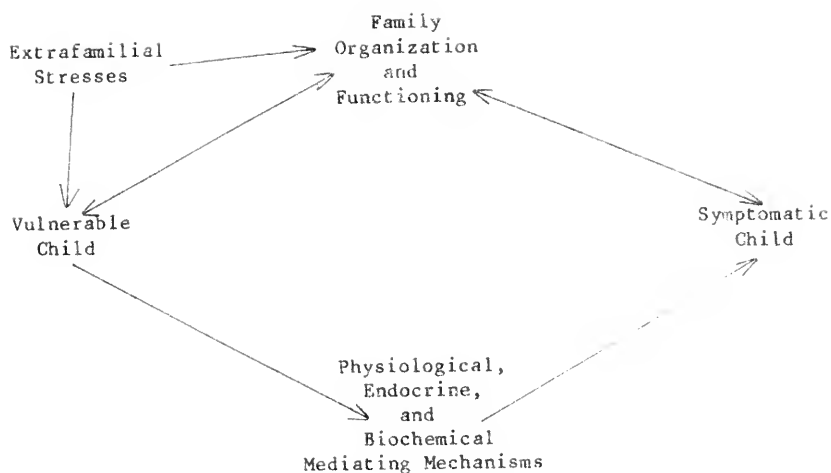


Figure 2.  
Open Systems Model of Disease  
(Minuchin et al., 1978)

somatic symptoms are related to a high level of family cohesion (enmeshment), and the suppression of differences and open conflict. Stewart (1962) found that illness is related to the suppression of aggressive and non-conforming feelings. In this long term prospective study relating subsequent disease to social and emotional adjustment, those persons presenting psychosomatic symptoms were found to show significantly better family and social adjustment than did those showing behavioral maladjustment.

In a study of families having a child with ulcerative colitis, Jackson and Yalom (1966) found that arguments and emotional comments were avoided and that there was a lack of tender affectionate interaction between the parents. Members of these families had a restricted number of roles within the family group. Communication was found to be exceedingly indirect. Many of the siblings of the symptomatic child were found to display symptoms of behavioral and/or psychological problems. Parents often thought of the symptomatic child as the least nervous and the most stable of the children, and questioned the possible connection between emotional distress and ulcerative colitis. Finally, the parents were restrictive, keeping the children within the family circle. While they commented on the children's lack of socialization, they did little or nothing about it.

Research on the relationship between family characteristics and level of control of diabetes also supports the family systems model. Koski and Kumento (1977) found poor control in diabetic children to be associated with unresolved family conflicts, a strong parent-child coalition, diffuse generational boundaries, social isolation of the



family and a lack of social support, denial of health and psychological problems on the part of the parents, and a focus on child problems rather than marital problems. Excellent control was associated with a stable family life, intact boundaries between generations, a realistic and responsible attitude toward diabetic care, and flexible problem solving. Siminds (1977) found an unusually low divorce rate in families of well-controlled patients compared to poor-controlled and non-diabetic comparison groups. Johnson (1980) interprets the results of this study as indicating that good control may be associated with unusually healthy or well-integrated families. Steinhausser et al. (1977) found that well-controlled patients reported their mothers to be highly supportive at disease onset, and to be less supportive over time. The opposite pattern was reported by patients with poor control. Other family patterns found to be associated with poor control include high levels of anxiety, overindulgence, overcontrol, resentment and rejection, and disinterest and neglect (Bruch, 1973; Katz, 1957; Khurana and White, 1970; Kravitz et al., 1971; Starr, 1955).

Several studies have found an association between family factors and the presence or exacerbation of symptoms of asthma. It has been noted in clinical reports and in controlled studies that about 40% of asthmatic children lose their symptoms immediately upon separation from their families through hospitalization (Coolidge, 1956; Peshkin and Abramson, 1959; Puncell et al., 1969) or attending boarding school (Bastians and Groen, 1955).

Research also supports the open systems model hypothesis that somatic symptoms can be treated by means of family therapy. For example, Lask and Matthews (1979) followed a group of children with moderate to severe chronic asthma. All children received regular medical care from a physician. In addition, children in the experimental group attended six one-hour family therapy sessions during a four-month treatment period. Results indicate that the experimental group showed significant improvement in their symptoms, while the control group did not show any improvement. Similarly, White et al. (1978) report that, during a two year study, family therapy was used successfully in improving the level of control of children's asthma. No empirical results were reported in this study.

Family therapy has also been found to be an effective intervention in the treatment of recurrent, non-organic pain in children. Recurrent pain is pain which occurs over a considerable period (months or years) and is severe enough to affect a child's appearance and/or activities (Apley et al., 1977). In a review of the limited literature on the various types of recurrent pain, Apley et al. found significant similarities between the different kinds of recurrent pains (i.e., in different anatomical locations), between the children with recurrent pains, and between the families of these children. They concluded that all types of recurrent pain in children should be conceptualized as a single disorder; that this disorder is an expression of emotional stress, and that it is an integral part of a family pattern of interaction. They suggest that, as a rule, these children should be treated through a comprehensive family oriented approach. Of the three studies which have evaluated

the effectiveness of family therapy in the treatment of recurrent pain, all reported significant positive results (Apley and Hale, 1973; Berger et al., 1977; White et al., 1978).

The literature also indicates that, in the treatment of anorexia, family therapy, and individual therapy which focuses on contemporary family dynamics, is an effective method of treatment. Consistently positive results have been reported Bruch (1973), Barcai (1971), Palazzoli (1974), and Minuchin et al., (1978). Vigersky (1977), in his review of the research on the treatment of anorexia, concludes that the family approach is the treatment of choice, being significantly more effective than psychoanalytic or behavioral methods.

#### Summary

The following conclusions about disease processes can be summarized from this literature review.

1. Manifest disease is not caused by any single, isolatable factor or event, but rather, is associated with the interaction of physiological, social, life event, and familial factors. This is supported by the fact that no one factor has been found which is associated with all cases of a given disease, that all persons experiencing a given factor do not manifest the disease, and that all persons with a given disease do not respond equally to a given intervention. This is in accordance with the General Systems Theory principles of hierarchical organization, wholeness, omnipotentiality, and equifinality.

2. The disease process can be conceptualized as a disorder or an extreme variation in the complex regulation processes of an organism or as the inability to respond successfully to environmental changes. This model of disease is in accordance with the General Systems Theory principles, as outlined by Miller et al. (1976) that dysfunctional systems are characterized by a disturbance in adaptation (i.e., extreme morphogenesis or homeostasis) and by a disturbance in cohesion (i.e., being either enmeshed or disengaged).

3. Given manifest disease, those adolescents who are less responsive to medical treatment will have experienced more stressful life events and/or will have low social support and/or will be a member of a less functional family system.

### CHAPTER III METHODOLOGY

The primary purpose of this study was to determine if, by assessing psychosocial factors, it were possible to differentiate adolescent patients whose chronic condition was in good medical control and were doing as well or better than expected from those who were in poor medical control and were not doing as well as expected. The literature reviewed indicates that the development and course of physical illness is related to the following three psycho-social factors: (a) family structure and functioning, (b) life stress, and (c) social support.

The secondary purposes of this study were to further test the family systems model of illness in children as proposed by Minuchin et al. (1979) which hypothesizes that chronically ill adolescents who are in poor medical control are members of dysfunctional families; and to test the psychosocial model of illness as proposed by Cobb (1976), Dean and Lin (1977), Kaplan et al. (1977), Nuckolls et al. (1972), and others, which hypothesizes that social support has a moderating effect on the adverse health effects of life stress.

### Subjects

The subjects of this study were the members of 48 families each having an offspring (age 14-19) with one of the following four types of chronic disorders: pulmonary (asthma, cystic fibrosis) ( $N=21$ ), gastroenterological (ulcerative colitis, Crohn's disease) ( $N=13$ ), cancer ( $N=11$ ), and juvenile rheumatoid arthritis ( $N=3$ ). All of the adolescent patients included in the study had received medical care for this condition through a specialty pediatrics outpatient clinic at Shands Teaching Hospital and Clinics for a minimum of six months prior to participation in the study.

During the data collection stage of the research 86 families were contacted and asked to participate in the study. Of these, two refused to participate when contacted. Thirty-four families which were contacted did not return questionnaires. Questionnaires were returned by 53 families. Of these, 23 returned questionnaires from the patient, mother, and father; 24 returned information from the patient and mother; one returned questionnaires from the patient and father; and five returned questionnaires from the patient only. Of the 53 families which returned data ("return group") five were dropped from the study because the level of medical response was not established. Of the 34 families which were contacted but did not return questionnaires ("no-return" group), five were dropped because the level of medical response was not established.

### Hypotheses

The following hypotheses will be tested in this study:

I.  $H_0$ : There will be no linear or quadratic combination of the variables of family functioning, life stress, and social support which will statistically distinguish between adolescents in very good medical control, adolescents in good medical control and adolescents in poor medical control.

II.  $H_0$ : The level of functioning of families with a chronically ill adolescent member in poor medical control will not be significantly different from the level of functioning of families with a chronically ill adolescent member in very good or good medical control.

$H_{a1}$ : Families of adolescents in poor medical control will be more likely to be functioning at the extremes of the Circumplex Model than will families of adolescents in very good or good medical control.

$H_{a2}$ : Families of adolescents in poor medical control will score significantly lower on the Family Functioning Index than will families of adolescents in very good or good medical control.

$H_{a3}$ : Families of adolescents in poor medical control will have more extreme scores on the Family APGAR than will families of adolescents in very good or good medical control.

III.  $H_0$ : The quantity of recent life change experienced by families of adolescents in poor medical control will not be

statistically different from the quantity of recent life change experienced by families of adolescents in very good or good medical control.

$H_a$ : Families of adolescents in poor medical control will have experienced more recent life change than will families of adolescents in very good or good medical control.

IV.  $H_0$ : The quantity of social support experienced by families of adolescents in poor medical control will not be statistically different from the quantity of social support experienced by families of adolescents in very good or good medical control.

$H_a$ : Families of adolescents in poor medical control will have experienced significantly less social support than will families of adolescents in good medical control.

V.  $H_0$ : The quantity of social support experienced by the families of adolescents in very good or good medical control (GMC families) which have experienced a high level of life change will not be significantly different from the quantity of social support experienced by the families of adolescents in poor medical control (PMC families) which have experienced a high level of life change.

$H_a$ : PMC families which have experienced high life change will have experienced significantly less social support than will GMC families which have experienced a high level of life change.



### Instrumentation

#### Family Adaptation and Cohesion Evaluation Scales (FACES)

FACES (Olson et al., 1982) is a 60-item self-report instrument designed as a tool for use by family therapists for diagnosing family problem behaviors and for setting treatment goals (see Appendix A). This instrument is a shortened and improved version of the original edition of FACES (Olson et al., 1979a), which contained 111 items. This assessment tool, which measures family functioning along the dimensions of "adaptability" and "cohesion", is based on the Circumplex Model of family functioning (Olson et al., 1979b).

This model, which is derived from General Systems Theory and is based on a review of the literature in the entire field of family behavior, proposes that adaptability and cohesion are the two most salient dimensions for describing family systems. "Cohesion" is defined as: "the emotional bonding members have for one another and the degree of individual autonomy a person experiences in the family" (Olson et al., 1979b, p. 5). "Adaptability" is defined as: "the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson et al., 1979b, p.12). In the Circumplex Model, these two independent dimensions are combined in such a way that families can be classified according to where they fall on both. By dividing each dimension into four levels: very low, low to moderate, moderate to high, and very high, a 4 X 4 matrix is formed defining 16 types of family functioning (see Figure 3).

C O H E S I O N

DISENGAGED  
 (Very Low)

SEPARATED  
 (Moderately Low)

CONNECTED  
 (Moderately High)

ENMESHED  
 (Very High)

A	CHAOTIC (Very High)	<u>Chaotically Disengaged</u>	Chaotically Separated	Chaotically Connected	<u>Chaotically Enmeshed</u>
D					
A					
P	FLEXIBLE (Moderately High)	Flexibly Disengaged	Flexibly Separated *	Flexibly Connected *	Flexibly Enmeshed
T					
A					
B					
I	STRUCTURED (Moderately Low)	Structurally Disengaged	Structurally Separated *	Structurally Connected *	Structurally Enmeshed
L					
I					
T					
Y	RIGID (Very Low)	<u>Rigidly Disengaged</u>	Rigidly Separated	Rigidly Connected	<u>Rigidly Enmeshed</u>

Figure 3.  
Sixteen Types of Marital and Family Systems Derived from the Circumplex Model  
(Olson et al., 1979a)

According to the Circumplex Model, the healthiest families are those which fall in the moderate ranges of both dimensions. These four types are designated by an asterisk (\*). The unhealthiest families are those at the extremes on both dimensions (those underlined in the four corners). Between these two are the eight types of families which are moderate on one dimension but extreme on the other.

FACES is comprised of statements concerning various aspects of family interaction and functioning. Each family member independently completes the questionnaire by indicating on a scale from one to five the degree to which each statement is felt to be true of her/his family. A "1" indicates that the statement is felt to be true of the family "almost never", while a "5" means it is true of the family "almost always".

Two primary scores are obtained, one for "cohesion" and one for "adaptability". The range for cohesion scores is from 27 to 135. The range for adaptability scores is from 23 to 115.

Analysis of data from 1000 families indicates that the internal consistency reliabilities for the total scores for adaptability and cohesion are high ( $r=.79$  and  $r=.92$  respectively). A factor analysis and item analysis are now being conducted by the authors.

As the revised edition of FACES is new, no studies have yet been reported using this version. However, the Circumplex Model, upon which FACES is based, does appear to have empirical validity in terms of differentiating families under stress and in setting treatment goals for family therapy (Olson et al., 1982; Olson et al., 1979b). Further, the validity of the original version of FACES in the study of disease is supported by a study conducted by Lewis (1981) on

factors affecting the psychosocial adjustment in chronically ill children and in their parents. Lewis found a significant relationship ( $p < .001$ ) between extreme FACES scores and the number of behavior problems reported in the children. Lewis also found that children in families with extreme FACES scores tended to have a lower self-concept ( $p = .059$ ) than children in families with moderate FACES scores.

This instrument was administered to parents and the adolescent patient. This measure was selected because it is derived from General Systems Theory, and it is specifically designed to assess family adaptability and cohesion. The importance of these two dimensions of family functioning in illness outcome has been shown in the work of Minuchin et al. (1979).

#### Family Functioning Index (FFI)

The FFI (Pless and Satterwhite, 1973) is a 15-item self-report instrument designed as a diagnostic tool for physicians to identify families with chronically ill children in need of special intervention services (see Appendix B). The unitary dimension of family functioning is measured by assessing the following areas: marital satisfaction, frequency of disagreements, communication, problem solving, and feelings of happiness and closeness.

FFI has an interobserver reliability of  $r = .72$  and a test-retest reliability of  $r = .83$ . Interobserver reliability was determined by comparing independently obtained FFI scores of husbands and wives (Pless and Satterwhite, 1973). Test-retest reliability was determined by a five year follow-up study (Satterwhite et al., 1976).

Validity of the instrument has been determined in several ways. FFI scores of registrants at family service agencies were compared to those of a random sample. Mean scores for agency families ( $\bar{X}=19.1$ ) were significantly lower than those for the random sample ( $\bar{X}=25.4$ ,  $p<.001$ ). Case workers, using a five-point rating scale designed to reflect the content of the FFI, also rated these families. The correlation between FFI scores of wives and case worker ratings were significant ( $r=.48$ ,  $p<.01$ ). The correlation between FFI scores of husbands and case worker ratings was also significant ( $r=.35$ ,  $p<.05$ ) (Pless and Satterwhite, 1973). In a separate study, lay counselors working with families with chronically ill children rated these families on the five-point scale. Correlation between these ratings and the mothers' FFI scores was  $r=.39$  ( $p<.01$ ) (Pless and Satterwhite, 1975). Low FFI scores have been associated with more behavioral problems and lower self-esteem in children (Pless et al., 1972) and non-compliant behavior among children with renal transplants (Kosch, 1978).

An augmented version of the FFI (Johnson, 1980) was used in this study. In this version five questions were added to the original instrument. These questions take into account "self" behaviors, whereas the original instrument assessed only "spouse" behaviors. This version yielded both an original version score and an augmented version score.

This instrument was administered to the parents only. The FFI was selected because it is the only established self-report measure of family functioning designed specifically for use with physically ill children.

### Family APGAR (APGAR)

The Family APGAR (Smilkstein, 1978) is a five-item self-report questionnaire designed as a diagnostic tool for physicians to measure global family functioning, and to identify patients with family difficulties (see Appendix C). Each of the five questions is designed to measure a family member's satisfaction with a different component of family functioning. The areas are adaptability, partnership, growth, affection, and resolve.

Inter-item correlations for the Family APGAR range from  $r=.24$  to  $r=.67$ . Split-half reliability is estimated at  $r=.93$ . Inter-observer reliability, determined by comparing independently obtained Family APGAR scores of husbands and wives, was found to be  $r=.67$  (Good et al., 1979).

Validity of the measure has been determined by comparing Family APGAR scores of clinical and non-clinical families, by comparing APGAR scores with FFI scores, and by correlating APGAR scores with therapist ratings of clinical families. Clinical families were found to score significantly lower than non-clinical families on overall index scores ( $p<.001$ ), and on four of the five items ( $p<.001$  for items #1, #2, and #3;  $p<.01$  for item #4). No difference was found on item #5, which assessed satisfaction with the amount of time spent with the family (Smilkstein, 1978). Following this study, item #5 was changed to reflect the quality, rather than the quantity of the time commitment of the family (Smilkstein, 1980). Validity data is not available for the revised form. The APGAR has been found to correlate with FFI scores ( $r=.80$ ,  $p<.01$ ). The APGAR has also been

found to correlate with therapist ratings of a clinical group of families ( $r=.64$ ,  $p<.01$ ).

Smilkstein (personal communication, 1980) has found that this instrument does not reliably detect "psychosomatic families in pathological equilibrium", but does detect "psychosomatic families in which a member is attempting to break away". Specific data in regard to these findings are not available. This instrument will be administered to parents and the adolescent patient. This instrument was selected because it is designed to assess the relationship between family functioning and medical outcome. This instrument was administered to parents and the adolescent patient.

#### Schedule of Recent Events (SRE)

The SRE (Holmes and Rahe, 1967b) is a 43-item self-report instrument designed to assist social scientists in the study of the relationship between social and life events and the onset and course of physical illness (see Appendix D). Subjects indicate whether or not they have experienced any of 43 described life events during the previous year. Each life event has been assigned a life change unit value (LCU), based on the judged magnitude of change in adjustment required by the life event. An individual's score is the arithmetic sum of the LCU values of the events experienced during the previous 12 months. Very high scores (450 or above) indicate a major life crisis. High scores (300-450) indicate a major life change. Moderate scores (150-300) indicate a minor life change.

Data indicate estimates of test-retest reliability of the SRE to be from .26 to .90, and to average around .60. Higher reliability

scores have been found with more intelligent and educated subjects, and over shorter periods of time ( $r=.90$  over two weeks;  $r=.26$  over 10 months) (Rahe, 1974).

Validity of the SRE has been supported through correlation of the scale with the PUP test, another measure of life events ( $r=.79$ ) (Hurst et al., 1978). Predictive validity has been demonstrated through a variety of studies which have found significant relationships between SRE scores and the subsequent onset of a variety of illnesses including diabetes mellitus (Kimball, 1971), tuberculosis (Holmes, 1954, 1957), cardiac disease (Rahe and Lind, 1971), and asthma (De Araujo et al., 1973).

This instrument was administered to parents only. This measure was selected because of its previously demonstrated utility in the study of the onset and course of a variety of medical conditions.

#### Life Events Record (LER)

The LER (Coddington, 1972b) is a 42-item self-report instrument designed to assist social scientists in the study of the relationship between social and life events and physical illness in adolescents (see Appendix E). Subjects indicate whether or not they have experienced each of 42 life events during the previous year. Each life event has been assigned a life change unit value (LCU), based on the judged magnitude of adjustment required by the life event. An individual's score is the arithmetic sum of the LCU values of the events experienced during the previous year. Based on a survey of 3620 randomly selected children, means and standard deviations have been established for social adjustment required by age.



Test retest reliability of the LER has not been reported. Predictive validity has been demonstrated through a variety of studies which have found a significant relationship between LER scores and the subsequent onset or exacerbation of a variety of illnesses, including juvenile rheumatoid arthritis (Heisel, 1972) and cancer (Jacobs and Charles, 1980).

This measure was administered to adolescent patients only. This instrument was selected because it is specifically designed to evaluate the relationship between life change events and the onset and course of illness in children.

#### A Short Scale for the Evaluation of Social Support (ASSESS)

ASSESS (Cohen and Reiss, 1981), is a 15-item self-report questionnaire designed to assess the quantity and quality of family and community support available to individuals under stress (see Appendix F). The following have been identified by one or more researchers or theorists as central to the concept and measurement of social support:

1. Enduring interpersonal ties to people and/or institutions that can be relied on to provide emotional support, help, reassurance, and feedback in times of need (Caplan, 1974; Berkman, 1977).

2. Networks of relationships, i.e., how interactive a person's social contacts are with each other (Kaplan et al., 1977).

3. The pattern of an individual's social affiliation (Murowski et al., 1978).

4. The number of "available others" to whom one can turn in times of need, and the degree of satisfaction with the available support (Saranson et al., 1981).

5. Information leading an individual to believe that s/he is cared for, is esteemed and valued, and belongs to a network of communication and mutual obligations (Cobb, 1976).

ASSESS was designed to measure these aspects of social support in the following manner:

1. Enduring interpersonal ties are measured by ASSESS items #1-#6. These items constitute the Berkman Social Network Index (Berkman, 1977), which assesses the availability of a confidant (spouse), contacts with close friends and relatives, church membership, and group membership. Test-retest reliability data is not available for this instrument. The predictive validity of this instrument was demonstrated in the study of the relationship between social support and mortality conducted by Berkman and Syme (1979) discussed earlier. In this study it was found that the age-adjusted relative rate of mortality for those scoring lowest on the Berkman Index compared with those having the highest scores on the Berkman Index was 2.3 for men ( $p < .001$ ) and 2.8 for women ( $p < .001$ ).

2. Network of relationships is measured by ASSESS item #7: "How many of your friends are friends with each other?"

3. The pattern of affiliation is measured by ASSESS item #8, which measures how often an individual sees, telephones, and writes important friends and relatives.

4. The number of "available others" and degree of satisfaction with support is measured by ASSESS items #9-#15. Items #9-#15 were

selected from the 27-item Social Support Questionnaire (Sarason et al., 1981). Item selection followed Cobb's (1976) conceptualization of social support as described above. Item #15 was designed to specifically assess social support for medically related problems. Each item asks the subject to identify the number of people to whom they can turn and on whom they can rely in a specified circumstance. Each item also asks the subject to indicate how satisfied s/he is with the available social support. Satisfaction is rated on a six-point Likert-type scale ranging from "very satisfied" to "very dissatisfied". Test-retest correlations (over a four week interval) for the Social Support Questionnaire are reported to be  $r=.90$  for "number of people" (N) scores, and  $r=.83$  for satisfaction (S) scores. The alpha coefficient of internal reliability for N and S scores are reported to be .97 and .94 respectively.

In order to establish the test-retest reliability of ASSESS, this instrument was given to volunteers at the Gainesville Florida Suicide Prevention and Crisis Intervention Center. The second administration was four weeks after the first. Thirty-eight volunteers completed ASSESS twice. Test-retest reliability was found to be .86.

This instrument was administered to parents and to the adolescent patient.

#### Physician's Form for Rating Level of Response to Medical Treatment

The physician's form for rating the patients' level of response to medical treatment is a one-item questionnaire designed

specifically for this study (see Appendix G). On this form, physicians were asked to rate each patient's response to medical treatment on a four-point Likert-type scale ranging from "very poor, much worse than expected" to "very good, much better than expected." The instructions stated that the rating should reflect the relative quality of response the patient had made to medical intervention, given the patient's disease. It was specifically stated that the rating should not reflect the relative level of medical compliance or the prognosis.

#### Procedures

Families were contacted by the investigator during an adolescent's outpatient visit to Shands Teaching Hospital and Clinics. Propsective subjects were told about the study and were informed that their participation would not affect the medical treatment received. They were also told that the information gained from the questionnaires would be kept confidential. If they chose to participate, family members were asked to read and sign the research informed consent form (Appendix H), and to complete the appropriate research questionnaire packets. Slightly different sets of questionnaires were given to parents and patients. Parents were administered FACES, the FFI, the Family APGAR, the Schedule of Recent Events and ASSESS. Adolescent patients were administered FACES, the Family APGAR, the Life Events Record, and ASSESS.

In order that subjects could complete the test battery in privacy, space was set aside adjacent to the pediatric clinic waiting

area for the completion of the questionnaire. Families were also given a stamped, addressed envelope, for returning questionnaires if they were not completed while waiting for the clinic appointment. If both parents were not with the child at the clinic, a questionnaire packet and consent form, and a stamped, addressed envelope was given to the family for the absent parent. A follow-up phone call was made three weeks later to all households which had not returned the questionnaire. A follow-up letter (with response postcard) was sent to all households which had not returned the questionnaires by six weeks after the clinic visit. A copy of the letter and response post card are contained in Appendix I.

At the conclusion of the data collection phase of the study physicians were asked to complete the physician's form for rating the level of response to medical treatment. Physicians were asked to rate only those patients with whom they were familiar.

## CHAPTER IV RESULTS

The transformations performed on the data from this study are described first in this chapter. Next, data concerning the physicians' rating of the level of medical response are described and data regarding the characteristics of the sample population are presented. Finally, the results of hypothesis testing are presented separately for each of the five major hypotheses.

### Data Transformations

In order to effectively test the five hypotheses in this study, four data transformations were performed. Each is described below.

The first transformation was done in order to be able to test Hypothesis II-1, which, in general, stated that adolescents in this study from the "worse" medical response group were more likely to come from families which function at extreme levels on the Circumplex Model dimensions of adaptability and cohesion than were adolescents from the "as expected" or the "better" response groups. This transformation calculated the value of the deviation of each subjects' adaptability and cohesion score from the mean (after Lewis, 1981). This was done in the following manner: First, using scores from the instrument Family Adaptation and Cohesion Evaluation Scales

(FACES), grand means were calculated for adaptability (ADP) and cohesion (COH) for adolescents, mothers, and fathers separately. These grand means are shown in Table 1.

Table 1. Grand Means and Standard Deviations of ADP and COH for Adolescents, Mothers and Fathers Data

Variable	N	Grand Mean	Standard Deviation
<u>Adolescents' scores</u>	48		
ADP		45.02	6.48
COH		58.41	9.63
<u>Mothers' scores</u>	42		
ADP		46.59	5.86
COH		61.78	9.60
<u>Fathers' scores</u>	21		
ADP		45.95	7.69
COH		64.00	9.56

Next, the deviation score was calculated for each subject on each of the two dimensions. These scores were calculated by taking the absolute value of the difference between a subject's score on a dimension and the appropriate grand mean for that dimension. The deviation score for adaptability (Dev ADP) can be represented in the following way:  $\text{Dev ADP} = |\overline{\text{ADP}} - \text{ADP}|$ , where ADP is the subjects adaptability score, and  $\overline{\text{ADP}}$  is the appropriate grand mean for adaptability. Similarly, the deviation score for cohesion (Dev COH) can be represented as  $\text{Dev COH} = |\overline{\text{COH}} - \text{COH}|$ .

The second transformation was also performed in order to be able to test Hypothesis II-1. This transformation calculated the distance between each subjects position on the Circumplex Model and the absolute center of the Circumplex Model (see Figure 3). This was

done in the following manner: First, using scores from the instrument FACES, standard deviations were calculated for adaptability (Sd ADP) and cohesion (Sd COH) for each family member group separately. These standard deviations are presented in Table 1. Z-scores were then calculated for each dimension. This calculation involved dividing subjects' Dev ADP by the appropriate ADP standard deviation score, and Dev COH by the appropriate COH standard deviation score. The Z-score can be represented in the following way:

$$\text{ADP } \underline{Z}\text{-score} = \text{Dev ADP} / \text{Sd ADP}$$

Next the distance from the center of the Circumplex Model intersect was calculated, in Z-score units. This score, hereafter referred to as the FACES score, was calculated by taking the square root of the sum of the Dev ADP Z-score squared and the Dev COH Z-score squared. The FACES score can be represented in the following way:

$$\text{FACES} = [(\text{Dev ADP } \underline{Z}\text{-score})^2 + (\text{Dev COH } \underline{Z}\text{-score})^2]^{1/2}$$

The third transformation was performed in order to be able to test Hypothesis II-3, which, in general, stated that adolescents in this study from the "worse" medical response group were more likely to come from families which had more extreme scores on the Family APGAR instrument than adolescents from the other two response groups. This transformation calculated the value of the deviation of each subject's Family APGAR (APGAR) score from the mean. This was done in a manner identical to that involved in deriving Dev ADP and Dev COH scores, and yielded a Dev APGAR score for each subject. The grand mean and standard deviation APGAR scores are shown in Table 2.



Table 2. Grand Means and Standard Deviations of Family APGAR Scores for Adolescents, Mothers and Fathers

Variable	N	Grand Mean	Standard Deviation
Adolescents' APGAR	48	7.98	2.09
Mothers' APGAR	42	7.38	2.81
Fathers' APGAR	21	7.76	2.67

The fourth data transformation was performed in order to be able to test Hypothesis V, which, in general, stated that adolescents in this study who came from families which experienced high levels of life change and low levels of social support were more likely to be in the "worse" medical response group. This transformation categorized subjects as to their relative level of life change and social support. First, subjects were rank ordered according to their life change score. Adolescents were rank ordered according to their Life Events Record (STRESS) scores. Mothers and fathers were rank ordered separately according to their Schedule of Recent Events (STRESS) scores. A median split was then performed on the distributions, and data from the centermost subject was discarded, when necessary. The uppermost and lowermost halves of the distributions were designated as high and low change, respectively. Table 3 reveals the mean and standard deviation scores for STRESS for each family member.

Next, subjects were rank ordered according to their scores on A Short Scale of the Evaluation of Social Support (ASSESS), and a median split was performed as with STRESS scores. Adolescents, mothers and fathers were rank ordered separately. The uppermost and

lowermost halves of the distributions were designated as high and low support respectively. Table 3 shows means and standard deviation scores for ASSESS for each family member.

Finally, subjects who fell into both the high STRESS and low ASSESS categories were classified as "at high risk", while subjects who fell into any of the other three categories were classified as "at low risk".

Table 3. Grand Means and Standard Deviations for High and Low ASSESS and High and Low STRESS Scores for Adolescents, Mothers and Fathers

Variable	High Stress		Low Stress	
	Mean	Standard Deviation	Mean	Standard Deviation
Adolescents	283.37	97.53	91.04	47.91
Mothers	263.35	104.12	96.90	42.15
Fathers	196.33	76.60	58.25	33.97

Variable	High Support		Low Support	
	Mean	Standard Deviation	Mean	Standard Deviation
Adolescents	24.87	2.75	16.96	2.66
Mothers	28.21	2.69	19.40	3.93
Fathers	26.72	3.40	17.77	3.52

With these transformations, each adolescent had the following ten scores: ASSESS, APGAR (Family APGAR), Dev APGAR, STRESS (Life Events Record), COH (cohesion dimension of FACES), Dev COH, ADP (adaptability dimension of FACES), Dev ADP, FACES (distance in Z-score units from the intersect of the Circulplex Model), and "at high risk" or "at low risk".

Each parent had the following twelve scores: ASSESS, APGAR (Family APGAR), Dev APGAR, STRESS (Schedule of Recent Events), COH

(cohesion dimension of FACES), Dev COH, ADP (adaptability dimension of FACES), Dev ADP, FACES (distance in Z-score units from the intersect of the Circulplex Model), FFI (Family Functioning Index), FFIA (Family Functioning Index Augmented form) and "at high risk" or "at low risk".

#### Rating of Level of Response to Medical Treatment

The level of response to medical treatment was rated for each patient by a pediatrician(s) familiar with the child's medical history. All adolescent patients included in the study had received care through a specialty pediatrics outpatient clinic at Shands Teaching Hospital and Clinics for at least six months prior to participation in the study.

At the conclusion of the data collection phase of the study, physicians were asked to rate their patients on the following four-point scale: (a) very poor, much worse than expected, (b) poor, worse than expected, (c) fair, about as expected, and (d) good, better than expected. Physicians could also indicate if they were unable to rate the patient (see Appendix G for a copy of the rating form).

Adolescents with asthma and cystic fibrosis were rated by three physicians from the Pulmonary Clinic. Of the 40 patients rated, 27 received the same rating from all physicians rating the case. Of these cases, five were rated by only two physicians. Of the remaining 18 cases, the patient was assigned the rating given by two of the three physicians. Three from this group were given a

different rating by each of the physicians and were dropped from the study.

Adolescents with cancer were rated by three physicians from the Hematology/Oncology Clinic. Of the 22 cancer patients, none were rated by all three physicians. Two doctors rated two patients apiece. Of these four patients, all received concordant ratings. One physician rated 18 patients, and four were not rated. These four were dropped from the study.

Patients with Crohn's disease and ulcerative colitis were rated by two physicians from the Gastroenterology Clinic. Of the 18 patients rated, 11 received the same rating from both physicians. Of the remaining seven, five were rated by only one physician. The two subjects who received discordant ratings were dropped from the study.

Patients with juvenile arthritis were rated by two physicians from the Infectious Diseases/Immunology Clinic. Of the eight patients rated, four received the same rating from both physicians, and three were rated by only one physician. The one patient who received discordant ratings was dropped from the study.

#### Sample Characteristics

Prior to the testing of the hypotheses, analyses were conducted to determine if questionnaires were returned by a representative sample of the families contacted, and if there were significant differences between the families from the four different disease groups.

Following the protocol described in the procedures section, 86 families were contacted and asked to participate in the study. Of these, two refused to participate when contacted, and 33 agreed to participate but returned no questionnaires. Of the 53 families which returned at least one questionnaire, 24 returned questionnaires from the patient, mother, and father; 23 returned information from the patient and mother; one returned questionnaires from the patient and father; and five returned questionnaires from the patient only. Of these 53 families which returned data ("return group"), five were dropped from the study because the level of medical response was not established through the physicians' ratings. Of the 33 families which were contacted but did not return questionnaires ("no-return" group), five were also dropped because the level of medical response was not established through the physicians' ratings.

No significant differences were found between the return and no-return groups in regard to their proportion of males and females ( $\chi^2(1)=.8$ ,  $p>.05$ ), or blacks and whites ( $\chi^2(1)=.67$ ,  $p>.05$ ). Also no significant differences were found between the two groups in regard to their proportion from each of the four disease groups ( $\chi^2(3)=4.0$ ,  $p>.05$ ), or from each of the three levels of medical control ( $\chi^2(2)=2.19$ ,  $p>.05$ ). An ANOVA revealed no significant difference between the mean age of adolescents from each group ( $F(1,76)=1.25$ ,  $p>.05$ ).

Table 4. Characteristics of the Return and No-Return Groups by Gender, Race, Level of Medical Response, and Age

	<u>Return</u>	<u>No-Return</u>	<u>Total</u>
Female	21	10	31
Male	27	20	47
Total	48	30	78
Black	9	8	17
White	39	22	61
Total	48	30	78
Cancer	11	7	18
Gastro.	13	3	16
Arthritis	3	4	7
Pulmonary	21	16	37
Total	48	30	78
Worse	9	10	19
As Expected	24	13	37
Better	15	7	22
Total	48	30	78
Mean Age	16.16	15.83	
Sd Age	2.01	1.48	
Age range	13-19	13-19	

#### Disease Group Characteristics

Several analyses were done to determine if there were any differences between the disease groups in regard to demographic, or psychosocial (predictor) variables.

For these analyses only, the alpha level was set at  $p < .10$ . This liberal alpha level was used in order to guard against making a Type II error, i.e., concluding that there was no difference between the disease groups on a predictor variable when, in fact, there was a difference. It was important to guard against Type II errors because

the low number of subjects in each disease group made it necessary to use the sample as a whole (collapsing across disease groups) to test the study hypotheses.

Comparisons using both return group and no-return group families indicated no significant differences among the disease groups in regard to the proportion of males and females ( $\chi^2(3)=5.3$ ,  $p>.10$ ). No significant difference was found among the mean ages of the adolescents from each of the four disease groups ( $F(3,74)=1.45$ ,  $p>.10$ ). A significant difference was found in regard to the distribution of blacks and whites among the disease groups ( $\chi^2(3)=9.94$ ,  $p<.05$ ). Significantly fewer blacks were in the gastroenterology group than expected ( $\chi^2(1)=9.94$ ,  $p<.05$ ). A significant difference was also found among the four disease groups in regard to the proportion of patients rated into each of the three levels of medical response ( $\chi^2(6)=11.91$ ,  $p<.10$ ). The proportion of juvenile rheumatoid arthritis patients rated as worse than expected ("worse") was significantly higher than expected ( $\chi^2(1)=3.1$ ,  $p<.10$ ); the proportion of gastroenterology patients rated as better than expected ("better") was also significantly higher than expected ( $\chi^2(1)=2.7$ ,  $p<.10$ ).

Table 5. Characteristics of the Three Levels of Medical Response Groups by Gender, Race, Levels of Medical Response, and Age

	Cancer	Gastro.	Juvenile Arthritis	Pulmonary	Total
Female	9	10	2	26	47
Male	9	6	5	11	31
Total	18	16	7	37	78
Black	2	0	3	12	17
White	16	16	4	25	61
Total	18	16	7	37	78
Worse	3	2	4	10	19
As Expected	8	6	2	21	37
Better	7	8	1	6	22
Total	18	16	7	37	78
Mean Age	16.81	15.38	16.33	16.28	
Sd Age	1.83	1.60	1.52	2.32	
Age range	13-18	13-19	14-19	13-19	

A three way ANOVA (disease group x gender x race) was then conducted on each of the 34 predictor variables (10 variables from each adolescent and 12 from each parent). Results revealed significant main effects for disease along three of the predictor variables. The results of these ANOVA's are contained in Table 6 (adolescents' data), Table 7 (mothers' data) and Table 8 (fathers' data).

A significant difference was found among the four disease groups on patients' ASSESS scores. Duncan's multiple range test revealed that adolescents with cancer reported significantly higher levels of social support than adolescents from the other three disease groups ( $p < .10$ ). A significant difference was also found on patients' FACES scores. Duncan's multiple range test indicated that adolescents with



Table 6

Means, Standard Deviations, and F Scores For Disease Group Main Effects for Adolescents' Scores (Across Race and Gender)

Variable	Cancer (N=11)		Gastroenterology (N=13)		Juvenile Arthritis (N=3)		Pulmonary (N=21)		F †	P Value
	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	25.00	3.03	19.23	4.26	20.66	2.08	19.85	5.13	4.23	.010***
STRESS	196.36	105.98	178.69	116.20	112.00	62.69	198.4	198.42	.47	.704
APGAR	8.54	1.75	8.00	2.34	7.66	.57	7.71	2.28	.37	.773
Dev APGAR	1.46	.75	1.85	.96	.34	.21	1.90	1.01	1.88	.147
ADP	46.54	4.20	46.00	7.62	42.66	3.21	43.95	7.08	.59	.626
Dev ADP	2.81	3.39	5.45	5.19	2.35	3.21	5.71	4.13	1.53	.221
OOH	59.63	5.37	58.46	10.15	59.00	3.46	57.66	11.80	.10	.961
Dev OOH	4.32	3.14	7.96	5.85	2.86	.47	8.65	7.82	1.72	.177
FACES	.68	.54	1.23	.92	.52	.40	1.40	.80	2.85	.049**

† N=48, df=3

\*\*\* significant at  $p=.01$

\*\* significant at  $p=.05$

Table 7

Means, Standard Deviations, and F Scores For Disease Group Main Effects for Mothers' Scores (Across Race and Sex)

Variable	Cancer (N=10)		Gastroenterology (N=13)		Juvenile Arthritis (N=3)		Pulmonary (N=15)		F †	p Value
	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	24.11	6.39	20.53	4.44	21.33	5.50	25.93	5.13	2.94	.046**
STRESS	211.70	121.74	172.69	71.78	48.00	38.11	180.81	134.90	.50	.687
APGAR	8.30	2.66	6.84	3.46	8.33	2.88	8.06	1.87	.73	.540
Dev APCAR	1.89	.89	2.71	1.02	2.41	1.34	1.46	.62	1.29	.291
ADP	45.30	4.73	45.69	7.04	45.33	3.51	48.37	5.79	.76	.525
Dev ADP	3.50	3.27	5.80	3.73	2.85	1.55	4.60	3.79	1.00	.402
COH	62.30	7.49	59.00	11.85	62.66	6.42	63.50	9.50	.52	.673
Dev COH	5.54	4.72	9.17	7.59	4.58	3.31	7.84	5.28	.98	.413
FACES	.93	.58	1.51	.77	.71	.34	1.27	.60	2.06	.123
FEL	26.00(a)	6.54	19.90(b)	7.72	23.00	11.31	26.55(c)	6.28	1.47††	.250
FELA	31.00(a)	7.09	24.30(b)	9.08	27.50	13.43	31.77(c)	7.47	1.37††	.279

† N=41, df=3

†† N=28, df=3

\*\* significant at  $p=.05$ 

(a) N=6

(b) N=10

(c) N=9

Table 8

Means, Standard Deviations, and F Scores For Disease Group Main Effects for Fathers' Scores (Across Race and Gender)

Variable	Cancer (N=4)		Gastroenterology (N=7)		Juvenile Arthritis (N=3)		Pulmonary (N=7)		F † Value	p Value
	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	26.00	5.00	21.00	7.09	26.00	3.60	21.57	4.82	.98	.429
STRESS	115.50	98.56	124.00	83.92	47.00	24.24	142.14	104.59	.08	.970
APGAR	6.25	4.50	7.85	2.73	8.33	2.08	7.14	2.41	.37	.777
Dev AFGAR	3.25	1.16	2.40	1.23	1.87	.93	1.80	.84	.70	.568
ADP	46.25	9.42	43.14	8.61	48.33	11.93	47.57	4.03	.46	.715
Dev ADP	6.27	6.04	5.97	6.45	8.31	6.86	3.03	2.93	1.20	.343
COH	63.00	10.70	60.28	11.78	67.00	10.14	67.00	6.50	.73	.550
Dev COH	7.50	6.45	9.14	7.58	7.00	6.55	5.00	4.86	.49	.697
FACES	1.22	.87	1.29	1.06	1.31	1.10	.74	.49	.68	.579
FFI	24.75	8.53	21.71(a)	6.79	23.00	5.00	27.20(a)	1.64	.83††	.500
FFIA	28.00	10.29	26.14(a)	7.79	28.66	3.51	33.20(a)	1.92	.97††	.435

† N=21, df=3

†† N=19, df=3

\*\* significant at  $\bar{p}=.05$ 

(a) N=6

pulmonary disease had more extreme scores on the Circumplex Model than adolescents with cancer or arthritis. The third significant difference was found between the disease groups on mothers' ASSESS scores. Duncan's multiple range test revealed that mothers of pulmonary patients reported higher levels of social support than mothers of gastroenterology patients ( $p < .10$ ).

While the ANOVA did not indicate a significant difference on patients' Dev COH scores ( $p = .177$ ), Duncan's test revealed that adolescents with pulmonary and gastroenterological diseases had more extreme scores on the dimension of cohesion than adolescents with cancer and arthritis ( $p < .10$ ). While the ANOVA did not indicate a significant difference on patients' Dev APGAR scores ( $p = .147$ ), Duncan's test indicated adolescents with arthritis had less extreme family functioning scores than adolescents with pulmonary and gastroenterological diseases ( $p < .10$ ). Finally, while the ANOVA did not indicate a significant disease main effect for mother's FACES scores ( $p = .12$ ), Duncan's test indicated that, on the Circumplex Model, the functioning of families with an adolescent with pulmonary disease is more extreme than that of families with an adolescent with arthritis ( $p < .10$ ).

Results for the gender analysis revealed main effects for three predictor variables. Fathers of male patients reported significantly less extreme scores on the dimension of adaptability (Dev ADP) than fathers of female patients ( $F(1,15) = 9.91$ ,  $p < .01$ ). Fathers of male patients also reported significantly less extreme (FACES) scores on the the Circumplex Model ( $F(1,15) = 4.89$ ,  $p < .05$ ). Mothers of male patients reported significantly lower social support scores than

mothers of female patients ( $F(1,35)=3.84, p<.05$ ). Means and standard deviations for significant variables for the main effect of gender are presented in Table 9. Means, standard deviations and  $F$  scores for all variables for the main effect of gender are contained in Table 25 (adolescents' data), Table 26 (mothers' data) and Table 27 (fathers' data) (see Appendix J).

Results for the race analysis revealed main effects for two predictor variables. Black patients achieved significantly lower life change scores ( $F(1,42)=4.23, p<.01$ ), and had significantly less extreme family functioning (APGAR) scores ( $F(1,42)=5.19, p<.05$ ), than did white patients. Means and standard deviations for significant variables for the main effects of race are presented in Table 9. Means, standard deviations and  $F$  scores for all variables for the main effect of race are contained in Table 28 (adolescents' data), Table 29 (mothers' data) and Table 30 (fathers' data) (see Appendix J).

Table 9. Means and Standard Deviations for Race and Gender  
Main Effects of Significant Predictor Variables

Variable	Black		White	
	Mean	Standard Deviation	Mean	Standard Deviation
<u>Adolescents' scores</u>				
STRESS	124.66	73.27	201.05	128.68
Dev APGAR	1.00	.85	1.85	1.23
	Females		Males	
	Mean	Standard Deviation	Mean	Standard Deviation
<u>Mothers' scores</u>				
ASSESS	25.05	5.65	22.37	5.37
<u>Fathers' scores</u>				
Dev ADP	8.91	5.42	2.18	2.72
FACES	1.55	.83	.69	.65

Because significant differences were found on some of the predictor variables with respect to disease, gender, and race, analyses employed to test the hypotheses of this study used residual scores rather than raw scores. Residual scores were calculated in the following manner. First means were calculated for each predictor variable for each disease, gender, and racial subgroup for adolescents, mothers, and fathers separately. These calculations yielded the following type of scores: mean APGAR score for all adolescents with pulmonary disease, mean APGAR score for all white adolescents, and mean APGAR score for all female adolescents. The residual scores were then calculated by subtracting from each subject's score for each variable the following three values: the

mean variable score for the subject's disease group, the mean variable score for the subject's gender group, and the mean variable score for the subject's racial group. (The grand mean of residual scores for a given variable is, by definition, zero.) In the following text and tables, residual scores are denoted with an "R/" preceeding the variable name. For example, the residual score for the variable ADP is denoted as "R/ADP".

Distinguishing Among the Three Levels of Medical Response  
By Using All the Predictor Variables

In order to test Hypothesis I three discriminant analyses were conducted. Hypothesis I stated, in general, that there was no linear or quadratic combination of predictor variables which would distinguish between the three levels of medical response at a rate significantly greater than chance. Each of the three analyses used data from a different family member. For the two analyses using parental data, the Family Functioning Index scores were deleted in order to maximize the number of subjects used to calculate the discriminant function.

The prior probabilities of response level membership used in the discriminant analyses were the proportions of response level membership found in the whole subject pool (return and no-return groups combined). These proportions were .25 from the "worse" group, .47 from the "as expected" group, and .28 from the "better" group. The proportion of patients which would be expected to be classified by chance from each of the three medical response levels, into each of the three response levels is shown in Table 10.

Table 10. Proportions of Patients Which Would Be Classified by Chance into a 3 x 3 Classification Table

<u>From</u> <u>Response Level</u>	<u>Into Response Level</u>			<u>Total</u>
	<u>Worse</u>	<u>As Expected</u>	<u>Better</u>	
<u>Worse</u>	.0625 <sup>°°</sup>	.1175 <sup>°</sup>	.0700 <sup>°</sup>	.2500
<u>As Expected</u>	.1175 <sup>°</sup>	.2209 <sup>°°</sup>	.1316 <sup>°</sup>	.4700
<u>Better</u>	.0700 <sup>°</sup>	.1316 <sup>°</sup>	.0784 <sup>°°</sup>	.2800
<u>Total</u>	.2500	.4700	.2800	

°° Correct classification

° Incorrect classification

The proportion of subjects which was expected to be correctly classified by chance is equal to the sum of proportions of patients from each of the subgroups which would be classified by chance into the correct subgroup. Therefore, the proportion of all patients which was expected to be classified correctly by chance equals .3618 (.0625 + .2209 + .0784).

The discriminant function calculated from adolescents' scores classified 41 of the 48 subjects correctly (85.41%). This proportion of correct classification was significantly greater than the proportion of correct classification expected by chance ( $Z=7.09$ ,  $p<.005$ ). Chi square analyses were then conducted to determine if, for each of the three classification subgroups, the proportion of patients classified correctly was significantly greater than the proportion expected to be classified correctly by chance. The proportion of patients classified correctly was significantly greater than chance for adolescents from the "worse" group ( $\chi^2(1)=10.96$ ,



$p < .005$ ); for adolescents from the "as expected" group ( $\chi^2(1)=6.65$ ,  $p < .01$ ); and for patients from the "better" group ( $\chi^2(1)=20.31$ ,  $p < .005$ ). The classification table for this analysis is shown in Table 11.

Table 11. Classification Table from Discriminant Analysis  
Based on Adolescents' Data

<u>From Response Level</u>	<u>Into Response Level</u>		
	Worse	As Expected	Better
<u>Worse</u>	9** (3.00)†	0° (5.64)	0° (3.36)
<u>As Expected</u>	0° (5.64)	19** (10.60)	5° (6.31)
<u>Better</u>	1° (3.36)	1° (6.31)	13** (3.76)
<u>Total</u>	10 (12.00)	20 (22.56)	18 (13.44)
			48 (48)

\*\* Correct classifications

° Incorrect classifications

† Numbers in parentheses are the number expected to be classified in the cell by chance.

The discriminant function calculated from mothers' data classified 27 of 41 patients correctly (65.85%). The proportion of patients correctly classified was significantly greater than the proportion which would be expected to be correctly classified by chance ( $Z=3.95$ ,  $p < .005$ ). Chi square analyses were also conducted, separately, on each of the three response level subgroups. Results of these analyses indicate that the proportion of patients correctly classified was significantly greater than chance for patients from the "as expected" group ( $\chi^2(1)=5.32$ ,  $p < .05$ ); and for patients from

the "better" group ( $\chi^2(1)=5.71$ ,  $p<.05$ ). The proportion of patients from the "worse" group classified correctly was not significantly greater than chance ( $\chi^2(1)=.07$ ,  $p>.05$ ). The classification table for this analysis is shown in Table 12.

Table 12. Classification Table from Discriminant Analysis Based on Mothers' Data

<u>From Response Level</u>	<u>Into Response Level</u>		
	Worse	As Expected	Better
<u>Worse</u>	3 <sup>°°</sup> (2.56)†	2 <sup>°</sup> (4.82)	2 <sup>°</sup> (2.87)
<u>As Expected</u>	2 <sup>°</sup> (4.82)	16 <sup>°°</sup> (9.06)	2 <sup>°</sup> (5.39)
<u>Better</u>	2 <sup>°</sup> (2.87)	4 <sup>°</sup> (5.39)	8 <sup>°°</sup> (3.21)
<u>Total</u>	7 (10.25)	22 (19.27)	12 (11.48)
			41 (41)

<sup>°°</sup> Correct classifications

<sup>°</sup> Incorrect classifications

† Numbers in parentheses are the number expected to be classified in the cell by chance.

The discriminant function calculated from fathers' data classified 16 of 20 patients correctly (85.00%). The proportion of patients correctly classified was significantly greater than the proportion of patients which would be expected to be correctly classified by chance ( $Z=4.45$ ,  $p<.005$ ). Chi square analyses were also conducted, separately, on each response level subgroup. Results of these analyses indicate that the proportion of patients classified correctly was significantly greater than chance for adolescents from the "better" group ( $\chi^2(1)=15.48$ ,  $p<.005$ ); and for adolescents from

the "worse" group ( $\chi^2(1)=8.45$ ,  $p<.005$ ). The proportion correctly classified was not significantly greater than chance for patients from the "as expected" group ( $\chi^2(1)=.04$ ,  $p>.05$ ). The classification summary table for this analysis is shown in Table 13.

Table 13. Classification Table from Discriminant Analysis  
Based on Fathers' Data

<u>From Response Level</u>	<u>Into Response Level</u>		
	Worse	As Expected	Better
<u>Worse</u>	5** (1.25)†	2° (2.35)	0° (1.40)
<u>As Expected</u>	1° (2.35)	4°° (4.42)	0° (2.63)
<u>Better</u>	1° (1.40)	0° (2.63)	7°° (1.57)
<u>Total</u>	7 (5.00)	6 (9.40)	7 (5.60)
			20 (20)

\*\* Correct classifications

° Incorrect classifications

† Numbers in parentheses are the number expected to be classified in the cell by chance.

All three of the discriminant functions correctly classified the patients from the subject pool at a rate significantly greater than chance. However, these proportions may be an overestimate of the proportion of patients from a different subject pool which would be expected to be correctly classified. The possible overestimation is due to the number of subjects used to calculate the discriminate function given the number of variables used in the function, and the number of classification groups. The number of subjects required to develop an unbiased discriminant function is calculated using the

formula:  $S = 50 + 10(x + c - 1)$ , where  $x$  is the number of variables used, and  $c$  is the number of classification groups.

In order to estimate the proportion of subjects from a new subject pool which would be correctly classified by the three discriminant functions derived above, a jackknife validation procedure was performed. In this procedure, data regarding one patient is deleted from the data used to calculate a discriminant function. This function is then used to classify the deleted patient. This patient is then returned to the data pool, and another is deleted and classified. This process is repeated until each patient is, in turn, deleted and classified.

The discriminant function calculated from adolescents' data classified 22 of the 48 patients correctly (45.58%). This proportion of correct classification was not significantly greater than the proportion of correct classification expected by chance ( $Z=1.36$ ,  $p>.05$ ). The proportion correctly classified was significantly greater than chance for patients from the "as expected" group ( $\chi^2(1)=3.88$ ,  $p<.05$ ). The proportion correctly classified was not significantly greater than chance for patients from the "better" group ( $\chi^2(1)=.01$ ,  $p>.05$ ). The proportion correctly classified from the "worse" group was not significantly less than expected by chance, ( $\chi^2(1)=.66$ ,  $p>.05$ ). The summary classification table is presented in Table 14.

Table 14. Classification Table from Jackknife Discriminant Analysis Based on Adolescents' Data

<u>From Response Level</u>	<u>Into Response Level</u>			<u>Total</u>
	<u>Worse</u>	<u>As Expected</u>	<u>Better</u>	
<u>Worse</u>	1° (3.00)†	7° (5.64)	1° (3.36)	9 (12.00)
<u>As Expected</u>	1° (5.64)	17° (10.60)	6° (6.32)	24 (22.56)
<u>Better</u>	2° (3.36)	9° (6.32)	4° (3.76)	15 (13.44)
<u>Total</u>	4 (12.00)	33 (22.56)	11 (13.44)	48 (48)

°° Correct classifications

° Incorrect classifications

† Numbers in parentheses are the number expected to be classified in the cell by chance.

Using the jackknife procedure, the discriminant analysis calculated from mothers' data classified 15 of the 41 patients correctly (36.58%). This proportion of correct classifications is not significantly greater than the proportion of correct classifications expected by chance ( $Z=.050$ ,  $p>.05$ ). Chi square analyses were also conducted, separately, on each response level subgroup. Results of these analyses indicate that the proportion of adolescents correctly classified was not significantly greater than chance for patients from the "better" group ( $\chi^2(1)=.192$ ,  $p>.05$ ); or for patients from the "as expected group" ( $\chi^2=.202$ ,  $p>.05$ ). The proportion of patients from the "worse" group correctly classified was not significantly less than expected by chance, ( $\chi^2(1)=1.6$ ,

$p > .05$ ). The classification summary table for this analysis is reported in Table 15.

Table 15. Classification Table from Jackknife Discriminant Analysis Based on Mothers' Data

<u>From Response Level</u>	<u>Into Response Level</u>		
	Worse	As Expected	Better
<u>Worse</u>	0** (2.56)†	4* (4.81)	3* (2.87)
<u>As Expected</u>	6* (4.81)	11** (9.05)	4* (5.39)
<u>Better</u>	3* (2.87)	6* (5.39)	4** (3.21)
<u>Total</u>	9 (10.25)	21 (19.27)	11 (11.48)
			41 (41)

\*\* Correct classifications

\* Incorrect classifications

† Numbers in parentheses are the number expected to be classified in the cell by chance.

Using the jackknife procedure, the discriminant analysis using fathers' data correctly classified seven of the 20 patients correctly (35.00%). This proportion of correct classifications was not significantly greater than the proportion of correct classifications expected by chance ( $z = .14$ ,  $p > .05$ ). Chi square analyses were also conducted, separately, on each response level subgroup. Results of these analyses indicate that the proportion of patients classified correctly was not significantly greater than chance for patients from the "worse" group ( $\chi^2(1) = 1.25$ ,  $p > .05$ ), or from the "better" group ( $\chi^2(1) = .60$ ,  $p > .05$ ). The proportion of patients correctly classified from the "as expected" group was not significantly less

than that expected by chance, ( $\chi^2(1)=1.78$ ,  $p>.05$ ). A summary of the classifications from this analysis is contained in Table 16.

Table 16. Classification Table from Jackknife Discriminant Analysis Based on Fathers' Data

<u>From Response Level</u>	<u>Into Response Level</u>			
	Worse	As Expected	Better	Total
<u>Worse</u>	3** (1.25)†	3* (2.35)	1* (1.40)	7 (12.00)
<u>As Expected</u>	2* (2.35)	1** (4.42)	2* (2.63)	5 (9.40)
<u>Better</u>	3* (1.40)	2* (2.63)	3** (1.57)	8 (5.60)
<u>Total</u>	8 (5.00)	6 (9.40)	6 (5.60)	20 (20)

\*\* Correct classifications

\* Incorrect classifications

† Numbers in parentheses are the number expected to be classified in the cell by chance.

Based on the data from the three discriminant analyses, Hypothesis I-1 is accepted at the .05 level. However, the results of the jackknife validation procedure indicated that these significant findings cannot be generalized to other subject populations. That is, the discriminant functions may not differentiate between the three response groups at a rate greater than chance (at the .05 level) for subjects from a new sample group.

Relationship Between Level of Medical Response and Family Functioning

Hypothesis II-1, in general, stated that adolescents whose response to medical treatment was worse than expected come from families that function at the extremes of the Circumplex Model. To test this hypothesis ANOVA's were performed which examined the differences among the three medical response level groups in the mean R/Dev COH, R/Dev ADP, and R/FACES scores. Table 17 shows the mean scores for each variable.

Table 17. Means and F Scores for ANOVA Examining Differences Among Levels of Response to Treatment on R/Dev ADP, R/Dev COH and R/FACES

	<u>Level of Response to Treatment</u>				
	<u>Worse</u>	<u>As Expected</u>	<u>Better</u>		
<u>Variable</u>	<u>Mean</u>	<u>Mean</u>	<u>Mean</u>	<u>F</u> <u>Value</u>	<u>P</u> <u>Value</u>
<u>Adolescents' scores</u>					
R/Dev ADP	.45	.36	-.84	.47	.629
R/Dev COH	-.65	-.16	.65	.15	.875
R/FACES	.03	.02	-.06	.10	.909
<u>Mothers' scores</u>					
R/Dev ADP	.80	-.49	.33	.47	.630
R/Dev COH	1.12	-1.40	1.55	1.41	.255
R/FACES	.18	-.17	.17	1.76	.185
<u>Fathers' scores</u>					
R/Dev ADP	-.70	-.47	.97	.40	.674
R/Dev COH	-2.83	1.36	1.45	1.41	.270
R/FACES	-.29	.04	.22	1.05	.369

Results of the ANOVA's for each of the three dimensions, as based on scores from each of the three family members, were not significant. Therefore Hypothesis II-1 is rejected at the .05 level.



Hypothesis II-2 stated, in general, that adolescents whose response to medical treatment was worse than expected come from families which score lower on the Family Functioning Index. In order to test this hypothesis ANOVA's were performed which examined the differences in mean FFI and FFIA scores among the three medical response groups. Table 18 summarizes the mean scores and F and p values for each variable.

Table 18. Means and F scores for ANOVA Examining Differences Among Levels of Response to Treatment on R/FFI and R/FFIA

Variable	<u>Level of Response to Treatment</u>			<u>F</u> Value	<u>p</u> Value
	<u>Worse</u>	<u>As Expected</u>	<u>Better</u>		
	Mean	Mean	Mean		
<u>Mothers' scores</u>					
R/FFI	1.92	-1.20	.33	.37	.692
R/FFIA	2.00	-1.33	.42	.32	.728
<u>Fathers' scores</u>					
R/FFI	-.47	2.99	-1.95	1.71	.211
R/FFIA	-1.00	2.91	-1.55	1.02	.381

Results of the ANOVA's for each of the two variables, as based on scores from each of the parents, were not significant. Hypothesis II-2 is rejected at the .05 level.

Hypothesis II-3 stated, in general, that patients whose response to medical treatment was worse than expected come from families which score significantly lower and/or have more extreme scores on the Family APGAR. To test this hypothesis ANOVA's were performed which examined the differences in mean R/APGAR and R/Dev APGAR scores

among the three medical response groups. The findings of these analyses are summarized in Table 19.

Table 19. Means and F Scores for ANOVA Examining Differences Among Levels of Response to Treatment on R/APGAR and R/Dev APGAR

Variable	<u>Level of Response to Treatment</u>			<u>F</u> Value	<u>P</u> Value
	<u>Worse</u>	<u>As Expected</u>	<u>Better</u>		
	Mean	Mean	Mean		
<u>Adolescents' scores</u>					
R/APGAR	-.70	-.12	.63	1.28	.287
R/Dev APGAR	-.39	.08	.10	.75	.479
<u>Mothers' scores</u>					
R/APGAR	-.49	.83	-1.00	.35	.704
R/Dev APGAR	.80	-.49	.33	2.65	.082
<u>Fathers' scores</u>					
R/APGAR	-.50	1.90	-.98	.12	.886
R/Dev APGAR	-.70	-.47	.97	.17	.846

Results of the ANOVA's for each of the two variables, as based on scores from each of the three family members, were not significant. Hypothesis II-3 is rejected at the .05 level.

As all of the three alternate hypotheses were rejected at the .05 level, Hypothesis II (null) is accepted at the .05 level.

Relationship Between Level of Response to Medical Treatment and  
Quantity of Life Change

Hypothesis III-1 stated, in general, that those adolescents whose response to medical treatment was worse than expected come from families which have experienced higher levels of recent life change. To test this hypothesis, ANOVA's were performed which examined the differences in mean R/STRESS scores among the three medical response groups. The results of these analyses are summarized in Table 20.

Table 20. Means and F Scores for ANOVA Examining Differences Among Levels of Response to Treatment on R/STRESS

Variable	<u>Level of Response to Treatment</u>			<u>F</u> Value	<u>p</u> Value
	<u>Worse</u>	<u>As Expected</u>	<u>Better</u>		
	Mean	Mean	Mean		
<u>Adolescents' score</u> R/STRESS	31.66	2.38	-22.80	1.15	.326
<u>Mothers' score</u> R/STRESS	-43.20	29.60	-21.69	.01	.989
<u>Fathers' score</u> R/STRESS	3.08	-4.17	1.99	.63	.538

Results of the three ANOVA's are not significant. Therefore Hypothesis III-1 is rejected at the .05 level, and Hypothesis III (null) is accepted at the .05 level.

Relationship Between Social Support and Quality of Response to  
Medical Treatment

Hypothesis IV-1 stated, in general, that adolescents whose response to medical treatment is worse than expected come from families which experience lower levels of social support. To test this hypothesis ANOVA's were performed which examined the difference in mean R/ASSESS scores among the three medical response groups. The results of these analyses are summarized in Table 21.

Table 21. Means and F Scores for ANOVA Examining Differences Among Levels of Response to Treatment on R/ASSESS

Variable	<u>Level of Response to Treatment</u>			<u>F</u> Value	<u>p</u> Value
	<u>Worse</u>	<u>As Expected</u>	<u>Better</u>		
	Mean	Mean	Mean		
<u>Adolescents' scores</u>					
R/ASSESS	-1.68	.74	-.17	1.15	.326
<u>Mothers' scores</u>					
R/ASSESS	-.92	-.47	1.14	.63	.538
<u>Fathers' scores</u>					
R/ASSESS	-1.59	1.20	.64	.57	.575

Results of the three ANOVA's are not significant. Therefore Hypothesis IV-1 is rejected at the .05 level, and Hypothesis IV (null) is accepted at the .05 level.

Interrelationship Among Life Stress and Social Support and the  
Quality of Response to Medical Treatment

Hypothesis V-1 stated, in general, that adolescents whose response to medical treatment was worse than expected come from families which have experienced the combination of a high level of life change and a low level of social support. To test this hypothesis two separate analyses were performed.

The first analysis used a Chi Square statistic. In order to do this analysis, subjects were rank ordered first according to their R/STRESS and then according to their R/ASSESS scores. Adolescents, mothers, and fathers were ranked separately. A median split was then performed, as described previously in the section on data transformations (page 65). Subjects who fell into both the high R/STRESS category and low R/ASSESS categories were classified as "at risk" while subjects who fell into any of the other three categories were classified as "at low risk". Table 20 presents the means and standard deviations of the uppermost and lowermost halves of the R/ASSESS and R/STRESS scores.

Table 22. Means and Standard Deviations for  
High and Low R/ASSESS and High and Low R/STRESS Scores for  
Adolescents, Mothers and Fathers

Family Member	High R/STRESS		Low R/STRESS	
	Mean	Standard Deviation	Mean	Standard Deviation
Adolescents	89.76	119.23	-89.74	90.34
Mothers	78.19	89.36	-78.09	81.35
Fathers	63.32	74.09	-63.30	77.72

Family Member	High R/ASSESS		Low R/ASSESS	
	Mean	Standard Deviation	Mean	Standard Deviation
Adolescents	.14	3.97	-.13	3.70
Mothers	.42	4.46	-.42	4.01
Fathers	1.25	6.01	-1.25	5.54

Three Chi Square analyses were then conducted. These analyses revealed no significant differences among the response groups in regard to the proportion of "high risk" and "low risk" families, as based on adolescents' scores ( $\chi^2(2)=2.90$ ,  $p>.05$ ); mothers' scores, ( $\chi^2(2)=1.85$ ,  $p>.05$ ); and fathers' scores ( $\chi^2(2)=1.26$ ,  $p>.05$ ). The distribution of "high risk" and "low risk" families, in each category of medical response is shown in Table 23.

Table 23. Distribution of "High Risk" and "Low Risk" Families by Levels of Response to Medical Treatment

	<u>High Risk</u>	<u>Low Risk</u>	<u>Total</u>
<u>Adolescents' scores</u>			
Worse	4	5	9
As Expected	6	18	24
Better	2	13	15
Total	12	36	48
<u>Mothers' scores</u>			
Worse	2	5	7
As Expected	6	14	20
Better	3	10	13
Total	11	29	40
<u>Fathers' scores</u>			
Worse	2	5	7
As Expected	2	3	5
Better	1	7	8
Total	5	15	20

In the second analysis, three MANOVA's were performed. These MANOVA's examined the relationship between mean R/STRESS and mean R/ASSESS scores and level of medical response, using scores from adolescents, mothers, and fathers separately. For each of the three analyses, the overall F and individual ANOVA's yielded no significant results. Results of the MANOVA's are presented in Table 24.

Table 24. F Scores for MANOVA's Examining Relationship Between  
R/STRESS and R/ASSESS Scores and  
Levels of Response to Treatment

	df	F Value	P Value
<u>Adolescents' scores</u>			
R/ASSESS	2	1.15	.326
R/STRESS	2	.61	.545
R/ASSESS / R/STRESS	(4,88)	.89	.473
<u>Mothers' scores</u>			
R/ASSESS	2	.63	.538
R/STRESS	2	2.63	.106
R/ASSESS / R/STRESS	(4,74)	1.46	.222
<u>Fathers' scores</u>			
R/STRESS	2	.03	.967
R/ASSESS	2	.57	.575
R/STRESS / R/ASSESS	(4,32)	.29	.885

Results of the Chi Square and MANOVA analyses were not significant. Hypothesis V-1 is rejected at the .05 level, and Hypothesis V (null) is accepted at the .05 level.

In summary, the results of the data analysis indicated that, for the subject sample, it was possible, using the psychosocial data, to differentiate among adolescents at the three levels of medical response at a rate greater than chance. Results of the jackknife validation procedure indicated that, given a new subject sample, the discriminant functions derived from parents' data might not differentiate among patients from the three response groups. This validation procedure also indicated that, given a new subject sample, the discriminant function derived from adolescents' data would identify members of the "as expected" group at a rate greater than



chance. This function would not, however, identify members of the "worse" or "better" groups at a rate greater than chance.

The results did not support the hypothesis derived from the Family Systems model that poor medical response is associated with dysfunctional family processes. The data also did not support the hypothesis derived from the psychosocial model of disease that life stress is associated with poor medical response and that social support moderates the adverse health effects of stress.

The results also indicate differences on the predictor variables among the four disease groups, between female and male patients, and between males and females.

## CHAPTER V DISCUSSION

### Discussion of Results

The results of the data analysis gave equivocal support to the basic hypothesis of this study; that the quality of response of chronically ill adolescents to medical treatment is affected by family and psychosocial factors. By utilizing data on the several predictor variables simultaneously it was possible to classify patients as to the quality of their medical response with a high degree of accuracy. However, the jackknife validation procedure indicated that the derived classification equations, based on mothers' and fathers' data, were sample specific; i.e., adolescents from a new random sample would not necessarily be correctly classified by level of medical response at a rate significantly greater than chance. The validation procedure did indicate that "as expected" patients would be classified correctly, but that the "better" and "worse" patients would not.

The results did not support the secondary hypotheses of this study; that poor response to medical treatment is associated with poor family functioning, that a high level of life stress is related to poor medical response, and that social support moderates the adverse effects which stress has on health.

Several possible conclusions may be drawn from this failure to find generalizable significant results. One interpretation is that there is, in fact, no relationship between quality of response to treatment and psychosocial factors. However, considerable theoretical and empirical evidence as presented in Chapter II of this study strongly suggests that some type of relationship does exist.

An alternative interpretation is that the nature of the relationship between quality of response to medical treatment and psychosocial factors may vary among diseases. This interpretation is supported by the unexpected significant differences which were found on the predictor variables among the four disease groups, between black and white patients, and between female and male patients. For example, in regard to differences among diseases, the data indicated that adolescents with cancer received more social support than patients with the other types of disorders; and mothers of children with pulmonary diseases received more social support than did mothers of children with gastroenterological disorders (regardless of the level of medical response). Results of the analysis of the adolescents' data indicated that the functioning of families with a child with a pulmonary or gastroenterological disorder was not as good as that of families with a child having cancer or arthritis.

In regard to the differences between female and male patients, mothers who had chronically ill daughters reported having significantly more social support than mothers who had ill sons. Further, based on fathers' FACES scores, the functioning of families with a sick boy (regardless of disease) was significantly more functional than that of families with a sick daughter. In regard to

the differences between white and black patients, black adolescents reported experiencing significantly less life change (stress) than white adolescents.

These unexpected findings suggest that there may be significant differences in the ways in which different chronic illnesses affect, and are affected by, family and psychosocial factors. These findings also suggest that families may be differentially affected by the illness of a child, depending on the gender of the child.

Another alternative hypothesis is that the nature of the relationship between the psychosocial factors and the quality of response may vary over the course of a disease. For example, medical response may be facilitated by cohesive and rigid family functioning at the time of diagnosis, but may be impeded by the same type of family functioning during a later stage of the disease. That is, early in treatment, the patient might be more vulnerable to the adverse effects of life stress or might be more in need of social support. Similarly, the age of the patient may affect the nature of the relationship. Younger patients might be more adversely affected by dysfunctional family dynamics, stress, and isolation than older ones.

#### Limitations

In evaluating the implications of the findings of this study for further research, several limiting factors must be considered. First, the proportion of the total sample from each disease group was not equal. While pulmonary patients made up 43% of the total "return" sample, arthritis patients made up only 6%; the two other

disease groups each made up approximately 25% of the sample. Further, there were no "worse" response level cancer patients or "better" response level arthritis patients in the data sample. A statistical procedure (using residual scores) was employed to minimize the effects of these sampling differences. However, the scarcity of subjects from some subgroups makes generalizations of the study results to these subgroups questionable.

Second, the return rate varied among the disease groups. This difference in return rate may be related to the manner in which families were introduced to the study. All of the families included in the study were contacted during outpatient visits to specialty pediatric clinics at Shands Teaching Hospital and Clinics. However, the quality of the setting and the interaction between subjects and the investigator differed among the specialty clinics. For example, most of the pulmonary families were contacted while waiting in the pulmonary functioning laboratory, a setting which was somewhat noisy and lacked privacy. Families visiting this clinic and the arthritis clinic were contacted directly by the investigator when he introduced the study. In contrast, families visiting the gastroenterology and oncology clinics, in most cases, were introduced to the investigator and to the study by an attending physician, who encouraged the families' cooperation. The investigator spoke to these families in the privacy of a medical examination room.

These differences in the character of the introduction may have had an effect on the return rate. Only 10 (29.41%) of the 34 hematology and gastroenterology families did not return any questionnaires, while 20 (45.45%) of the 44 pulmonary and arthritis

families did not return forms. Statistical analysis reveals a trend for the proportion of non-returns of cancer and gastroenterology patients to be lower than expected ( $\chi^2(1)=2.98$ ,  $p<.10$ ); and for the proportion of non-returns to be greater than expected for pulmonary and arthritis patients ( $\chi^2(1)=2.88$ ,  $p<.10$ ).

The difference in return rate may have also been related to the level of stress experienced by families visiting the various clinics. For example, patients and parents visiting the oncology clinic were probably under the most stress since the majority of these patients received chemotherapy during the visit. For these families, there appears to be a relationship between the return rate and the quality of response to medical treatment. Of the three "worse" response level cancer patients, none returned a questionnaire, while six of the seven "better" patients did return data.

A second limiting factor of this study is the limited number of subjects in the sample pool. The existence of the hypothesized relationships between medical response and the psychosocial factors may have been masked by the limitations of statistical procedures when used on small samples. As was noted above, some "disease type x response level" cells were empty. Further, in order to have calculated a population (rather than sample specific) discriminant function, given the number of variables and classification groups employed, data would have been needed from approximately 200 patient families. As the discriminant analysis did yield significant (although sample specific) results, further study should use a larger subject pool.

A third limiting factor of this study is related to the rating, by physicians, of the level of medical response. A comparison of the proportions of patients from each of the disease groups rated at each of the levels of medical response revealed significant differences. From the population of all families contacted, the proportion of arthritis patients whose level of response was rated "worse" was higher than expected (57%), as was the proportion of gastroenterology patients rated as "better" (50%). For the group as a whole, 24% were rated "worse than expected", 47% were rated "about as expected", and 28% were rated "better than expected".

These differences between expected and observed proportions could be due, in part, to at least three factors. First, these differences could be due to random sampling effects. The statistical procedures indicate, however, that the probability of this being true for this sample is one in ten. Second, these differences could be due to some subpopulation differences related to the character of patients seen by the different clinics. In other words, the proportion of patients who are seen by the arthritis clinic, whose response to treatment is worse than expected, may be higher than the proportion seen in other clinics. Third, these differences may be due to a rating bias on the part of the physicians. Physicians from the different clinics may have been more or less willing to categorize their patients as doing poorly; i.e., physicians may have perceived the ratings as relating to their success or failure in treating their patients. Fourth, differences may be an artifact of the rating scale, and the looseness of the categorization criteria. The relative nature of the rating scheme may also have been too

vague. (The rating instructions were: "compared to other patients with the same disease, is this patient's response to medical treatment worse than, better than, or about as expected.") Since the rating categories used in this scale were utilized in no previous study reviewed in the literature, no expectations could be given to physicians regarding the proportion of patients expected to fall into each response category. One alternative to the use of the three categorical levels is to have physicians rank order patients by the quality of response to treatment. This alternative was considered for this study, but was rejected after consultation with physicians, who felt the ranking for more than 10-15 patients would be too time consuming.

#### Recommendations for Further Study

The results of this study give only equivocal support to the thesis that there is a relationship between psychosocial factors and quality of response to medical treatment. However, these results, together with the methodological problems encountered in this study, do have implications for further research in this area.

First, during this project, several physicians expressed an interest in learning more about the impact of psychosocial factors on the course of chronic illness in adolescents. This indicates that some members of the medical community will support this type of research.

Second, observed differences in the return rate among the various clinics indicates that, in order to gain cooperation from the



subjects, a study must have the active, explicit support of physicians. The differential return rates also point out the importance of the setting in which a study is introduced.

Third, the zero return rate for "worse" response level cancer patients points out the difficulty of gaining the cooperation of highly stressed families and very sick patients in psychological research. The clinical application of this line of research is the early identification of that group of patients whose response to treatment will be worse than expected. Therefore, subsequent studies along this line should make special arrangements to facilitate the cooperation of the most stressed and "worse" response level group. It appears that an attending physician's request for the completion of psychosocial questionnaires and/or making the questionnaires a standard part of the history or intake procedure would be necessary.

Fourth, the problems encountered with the rating of the level of medical response points out the need to revise the method. If this classification scheme were to be used in the future, it would be important to (a) develop broad general and disease specific criteria for the classification categories, (b) have physicians rate a large number of patients to determine relative expected frequencies, and (c) develop a mechanism by which the level for patients who are difficult to rate can be deliberated and determined (it may be that the "problem ratings" constitute a distinct patient group).

Fifth, the Family Functioning Index appears not to be an efficient or effective instrument for use in this line of research. This instrument was the longest and most difficult to complete. It also has limited application since it can be completed only by

families headed by two parents (approximately 37% of the families in this study were headed by a single parent).

Finally, the data failed to strongly support the thesis that the quality of response to medical treatment is related to psychosocial factors. Therefore, more sophisticated approaches should be adopted. For example, a relationship may be detected if families were evaluated over time, and changes in quality of medical response were related to changes in the quality of family functioning, or quantity of social support and stress.

Another approach would be first, to identify and assess the families of adolescents whose response is "poor", and then to provide intervention services designed to improve family functioning and social support. It could then be determined if an improvement in these areas was associated with an improvement in the quality of response to medical treatment.

#### Summary

The present study was an attempt to examine the relationship between family and psychosocial factors and the quality of response of chronically ill adolescents to medical treatment. Previous research has generally supported the thesis that the development and course of physical illness is related to the following psychosocial factors: family functioning and structure, life stress, and social support. The primary purpose of the present study was to determine if, by assessing these three factors, it was possible to differentiate between adolescents whose chronic medical condition was

in satisfactory control from those adolescents whose medical condition was in unsatisfactory control. The secondary purpose of this study was to further test the family systems model of illness. This model hypothesizes that chronically ill adolescents who are in unsatisfactory control are members of dysfunctional families. A further purpose was to test the psychosocial model of illness which hypothesizes that social support moderates the adverse effects life stress has on health.

To test these hypotheses, data was obtained from families each having an offspring (age 14-19) with one of the following four types of chronic disorders: pulmonary (asthma, cystic fibrosis) ( $N=21$ ); gastroenterological (ulcerative colitis, Crohn's disease) ( $N=13$ ); cancer ( $N=11$ ); juvenile arthritis ( $N=3$ ). Parents from each family were administered the Family Adaptation and Cohesion Evaluation Scales (FACES), the Family Functioning Index (FFI), the Family APGAR (APGAR), the Schedule of Recent Events (SRE), and A Short Scale for the Evaluation of Social Support (ASSESS). Adolescent patients were administered FACES, APGAR, ASSESS, and the Life Events Record (LER).

The testing of the hypotheses utilized the data from mothers, fathers, and adolescents separately. Results of the data analysis indicated that it was possible, using the psychosocial data, to calculate a discriminate function which distinguished among adolescents in very good medical control, adolescents in good medical control, and adolescents in poor control at a rate significantly greater than chance. The jackknife validation procedure indicated that, given a new sample population, the discriminant function derived from adolescents' data would identify members of the "as

expected" response group at a rate greater than chance, but would not differentiate members of the "worse" or "better" response groups. The validation procedure indicated that the discriminate functions derived from mothers' and fathers' data would not differentiate between any of the response groups at a rate greater than chance.

The results did not support the family systems notion that poor medical response is associated with poor family functioning. The results also did not support the notion that life stress is associated with poor medical response or that social support moderates the adverse effect which stress has on health.

APPENDIX A  
FAMILY ADAPTATION AND COHESION EVALUATION SCALES

(Olson, Portner, & Bell, Note 1)

Please indicate how often the following statements are true about your family. Please use the following response categories:

---

1	2	3	4	5
Almost never	Once in awhile	Sometimes	Frequently	Almost always

---

- \_\_\_\_\_ 1. Family members are supportive of each other during difficult times.
- \_\_\_\_\_ 2. In our family, it is easy for everyone to express his/her opinion.
- \_\_\_\_\_ 3. It is easier to discuss problems with people outside the family than with other family members.
- \_\_\_\_\_ 4. Each family member has input in major family decisions.
- \_\_\_\_\_ 5. Our family gathers together in the same room.
- \_\_\_\_\_ 6. Children have a say in their discipline.
- \_\_\_\_\_ 7. Our family does things together.
- \_\_\_\_\_ 8. Family members discuss problems and feel good about the solutions.
- \_\_\_\_\_ 9. In our family, everyone goes his/her way.
- \_\_\_\_\_ 10. We shift household responsibilities from person to person.
- \_\_\_\_\_ 11. Family members know each other's close friends.
- \_\_\_\_\_ 12. It is hard to know what the rules are in our family.
- \_\_\_\_\_ 13. Family members consult other family members on their decisions.
- \_\_\_\_\_ 14. Family members say what they want.
- \_\_\_\_\_ 15. We have difficulty thinking of things to do as a family.
- \_\_\_\_\_ 16. In solving problems, the children's suggestions are followed.
- \_\_\_\_\_ 17. Family members feel very close to each other.
- \_\_\_\_\_ 18. Discipline is fair in our family.
- \_\_\_\_\_ 19. Family members feel closer to people outside the family than to other family members.
- \_\_\_\_\_ 20. Our family tries new ways of dealing with problems.
- \_\_\_\_\_ 21. Family members go along with what the family decides to do.

- \_\_\_\_\_ 22. In our family, everyone shares responsibilities.
- \_\_\_\_\_ 23. Family members like to spend their free time with each other.
- \_\_\_\_\_ 24. It is difficult to get a rule changed in our family.
- \_\_\_\_\_ 25. Family members avoid each other at home.
- \_\_\_\_\_ 26. When problems arise, we compromise.
- \_\_\_\_\_ 27. We approve of each other's friends.
- \_\_\_\_\_ 28. Family members are afraid to say what is on their minds.
- \_\_\_\_\_ 29. Family members pair up rather than do things as a total family.
- \_\_\_\_\_ 30. Family members share interests and hobbies with each other.

APPENDIX B  
FAMILY FUNCTIONING QUESTIONNAIRE

(Pless and Satterwhite, Note 2)

1. What sort of things do you do as a family?

a. In the evenings -

b. On the weekends -

c. On vacations-

(Put a check mark in the box to indicate your answer.)

2. How do you think the children get along together compared with other families?  
(Skip this question if you have only one child.)

☐ better      ☐ same      ☐ worse

3. Do the children find it easy to talk to you spouse about their problems?

☐ yes      ☐ sometimes      ☐ no

Do the children find it east to talk to you about their problems?

☐ yes      ☐ sometimes      ☐ no

4. Do you find your spouse an easy person to talk to when something is bothering you?

☐ yes      ☐ sometimes      ☐ no

Do you think your spouse finds you an easy person to talk to when something is troubling him/her?

☐ yes      ☐ sometimes      ☐ no

5. Is you spouse able to spend a lot of time with the children in the evening?

☐ yes      ☐ sometimes      ☐ no

Are you able to spend a lot of time with the children in the evening?

☐ yes      ☐ sometimes      ☐ no

6. Is your spouse able to spend a lot of time with the children on the weekend?

☐ yes      ☐ sometimes      ☐ no

Are you able to spend a lot of time with the children on the weekend?

☐ yes      ☐ sometimes      ☐ no

7. Would you say, in general, your family is happier than most other families you know, or is about the same, or is less happy?

☐ happier      ☐ same      ☐ less happy

8. What was the most important problem that your family had to deal with this year? \_\_\_\_\_

a. Was a solution found?

☐  
yes

☐  
no

b. Did you discuss the problem with your spouse?

☐  
yes

☐  
no

c. Was everyone satisfied with the solution?

☐  
yes

☐  
no

9. In every family someone has to decide such things as where the family will live and so on. Many couples talk about such things with the family first, but the final decision often has to be made by the husband or the wife. If these are situations you have not decided on recently, how would they be decided on should they occur. (Write in the number corresponding to your choice in the box following each question.)

1 = Husband always
2 = Husband more than wife
3 = Husband and wife the same
4 = Wife more than husband
5 = Wife always

a. Who usually makes the final decision about what kind of car to get?

b. About whether or not to buy some life insurance?

c. About what house or apartment to take?

d. About what job the husband should take?

e. About whether the wife should go to work or should quit work?

f. About how much the family can afford to spend per week on food?

g. About what doctor to have when someone is sick?

h. About where to go on vacation?



10. Thinking of marriage in general which one of these five things would you say is the most valuable part of marriage? (Write in the number corresponding to your choice using each number only once).

- 1 = The chance to have children  
 2 = The standard of living - the kind of house, clothes, car, and so forth.  
 3 = The husband's/wife's understanding of their spouse's problems and feelings.  
 4 = The husband's/wife's expression of love and affection for their spouse  
 5 = Companionship in doing things together with the spouse.

- a. The most valuable part of marriage  
 b. The next most valuable  
 c. Third most valuable  
 d. Fourth most valuable  
 e. Fifth most valuable


11. Of course, most couples differ sometimes over things, when you and your spouse differ about something, do you usually give in and do it your spouse's way or does he/she usually come around to your point of view?

☐

spouse's

☐

50/50

☐

my way

12. Would you say disagreements in your household come up more often, about the same, or less often than in other families you know?

☐
More  
often
☐

Same

☐
Less  
often

13. Would you say that compared to most families, you know, you feel less close to each other, about the same, or closer than other families do?

☐
Less  
close
☐

Same

☐

Closer

14. The following are some feelings you might have about certain aspects of marriage. (Write in the number corresponding to your choice).

- 1 = Pretty disappointed. I'm really missing out on that.
- 2 = It would be nice to have more.
- 3 = It's all right, I guess. I can't complain.
- 4 = Quite satisfied. I'm lucky the way it is.
- 5 = Enthusiastic. It couldn't be better.

- a. How do you feel about your standard of living, the kind of house, clothes, car, and so forth? ☐
- b. How do you feel about the understanding you get of your problems and feelings? ☐
- c. How do you feel about the love and affection you receive? ☐
- d. How do you feel about the companionship of doing things together? ☐

15. When your spouse comes home from work, how often does he/she talk about things that happened there? (Disregard if your spouse does not work).

☐

Very  
often

☐

Sometimes

☐

Never

☐

Does not  
work

- When you come home from work, how often do you talk about things that happened there? (Disregard if you do not work).

☐

Very  
often

☐

Sometimes

☐

Never

☐

Does not  
work

APPENDIX C  
FAMILY APGAR

(Smilkstein, Note 3)

The following questions have been designed to help us better understand you and your family. You should feel free to ask questions about any item in the questionnaire.

Comment space should be used when you wish to give additional information, or if you wish to discuss the way the question applies to your family. Please try to answer all questions.

For each question,  
check only one box

I am satisfied that I can turn to my family\* for help when something is troubling me.

Comments:

I am satisfied with the way my family talks over things with me and shares problems with me.

Comments:

I am satisfied that my family accepts and supports my wishes to take on new activities or directions.

Comments:

I am satisfied with the way my family expresses affection, and responds to my emotions, such as anger, sorrow, or love.

Comments:

I am satisfied with the way my family and I share time together.

Comments:

Almost always	Some of the time	Hardly ever

\* "Family" is the individual(s) with whom you usually live. If you live alone, consider family as those with whom you now have the strongest emotional ties.

APPENDIX D  
SCHEDULE OF RECENT EVENTS

(Holmes and Rahe, Note 4)

Instructions: Please identify, with a check mark, each one of the following life events which have occurred to you in the last year.

- \_\_\_ 1. Marriage
- \_\_\_ 2. Troubles with the boss
- \_\_\_ 3. Detention in jail or other institution
- \_\_\_ 4. Major change in sleeping habits (a lot more or a lot less sleep, or change in time of day when you sleep)
- \_\_\_ 5. Death of spouse
- \_\_\_ 6. Death of a close family member
- \_\_\_ 7. Major change in eating habits (a lot more of a lot less food intake, or very different meal times)
- \_\_\_ 8. Foreclosure on a mortgage or loan
- \_\_\_ 9. Revision of personal habit (dress, manners, friends)
- \_\_\_ 10. Death of a close friend
- \_\_\_ 11. Minor violations of the law (traffic tickets, jay walking, or disturbing the peace, for example)
- \_\_\_ 12. Outstanding personal achievement
- \_\_\_ 13. Pregnancy
- \_\_\_ 14. Major change in health or behavior of a family member
- \_\_\_ 15. Sexual difficulties
- \_\_\_ 16. In-law trouble
- \_\_\_ 17. Major change in number of family get-togethers
- \_\_\_ 18. Major change in money matters (better or worse)
- \_\_\_ 19. Gaining a new family member, (in your home)
- \_\_\_ 20. Change in residence
- \_\_\_ 21. Child leaving home (marriage, attending college, etc.)
- \_\_\_ 22. Marital separation from mate
- \_\_\_ 23. Major change in church activities
- \_\_\_ 24. Marital separation from mate
- \_\_\_ 25. Being fired from work
- \_\_\_ 26. Divorce
- \_\_\_ 27. Changing to a different line of work
- \_\_\_ 28. Major change in the number of arguments with spouse (either more or less than usual)
- \_\_\_ 29. Major change in responsibilities at work (promotion, demotion, department transfer)
- \_\_\_ 30. Spouse beginning or ceasing work outside home
- \_\_\_ 31. Major change in working hours or conditions
- \_\_\_ 32. Major change in usual type or amount of recreation
- \_\_\_ 33. Taking on a mortgage or loan greater than \$10,000 (for purchasing a home, business, etc.)
- \_\_\_ 34. Taking on a mortgage or loan less than \$10,000 (for purchasing a car, TV, freezer, etc.)

- \_\_\_\_\_ 35. Major personal injury or illness
- \_\_\_\_\_ 36. Major business readjustment (merger, bankruptcy, etc.)
- \_\_\_\_\_ 37. Major change in social activities (clubs, dancing,  
movies, visiting, etc.)
- \_\_\_\_\_ 38. Major change in living conditions (building a new home,  
remodeling home, deterioration of home or neighborhood)
- \_\_\_\_\_ 39. Retirement from work
- \_\_\_\_\_ 40. Vacation
- \_\_\_\_\_ 41. Christmas
- \_\_\_\_\_ 42. Changing to a new school
- \_\_\_\_\_ 43. Beginning or ceasing formal schooling

APPENDIX E  
LIFE EVENTS RECORD

(Coddington, Note 5)

Instructions: Please identify, with a check mark, each one of the following life events which have occurred to you in the last year.

- \_\_\_\_\_ 1. Birth of a brother or sister
- \_\_\_\_\_ 2. Increase in number of arguments with parents
- \_\_\_\_\_ 3. Fathering a child
- \_\_\_\_\_ 4. Death of a parent
- \_\_\_\_\_ 5. Not making an extracurricular activity you wanted to be involved in (athletic team, band, etc.)
- \_\_\_\_\_ 6. Mother beginning to work
- \_\_\_\_\_ 7. Death of a close friend
- \_\_\_\_\_ 8. Suspension from school
- \_\_\_\_\_ 9. Being accepted at college of your choice
- \_\_\_\_\_ 10. Becoming pregnant
- \_\_\_\_\_ 11. Pregnancy in unwed teenage sister
- \_\_\_\_\_ 12. Death of a grandparent
- \_\_\_\_\_ 13. Addition of adult to family (grandparent, for example)
- \_\_\_\_\_ 14. Decrease in number of arguments with parents
- \_\_\_\_\_ 15. Beginning to date
- \_\_\_\_\_ 16. Serious illness requiring hospitalization of brother or sister
- \_\_\_\_\_ 17. Serious illness requiring your hospitalization
- \_\_\_\_\_ 18. Change in parents' financial status
- \_\_\_\_\_ 19. Jail sentence of a parent for 30 days or less
- \_\_\_\_\_ 20. Decrease in number of arguments your parents have
- \_\_\_\_\_ 21. Increase in number of arguments your parents have
- \_\_\_\_\_ 22. Discovery of being an adopted child
- \_\_\_\_\_ 23. Marriage of parent to stepparent
- \_\_\_\_\_ 24. Breakup with girlfriend or boyfriend
- \_\_\_\_\_ 25. Having a visible physical handicap
- \_\_\_\_\_ 26. Change in father's job requiring him to be away from home more
- \_\_\_\_\_ 27. Becoming a full fledged member of a church
- \_\_\_\_\_ 28. Failure of a grade in school
- \_\_\_\_\_ 29. Acquiring a visible physical deformity
- \_\_\_\_\_ 30. Getting married
- \_\_\_\_\_ 31. Change in your relationships with your friends
- \_\_\_\_\_ 32. Death of a brother or sister
- \_\_\_\_\_ 33. Brother or sister leaving home
- \_\_\_\_\_ 34. Serious illness requiring hospitalization of parent

- \_\_\_\_\_ 35. Beginning to use drugs or alcohol
- \_\_\_\_\_ 36. Divorce of parents
- \_\_\_\_\_ 37. Move to a new school district
- \_\_\_\_\_ 38. Outstanding personal achievement
- \_\_\_\_\_ 39. Loss of job by parent
- \_\_\_\_\_ 40. Marital separation of parents
- \_\_\_\_\_ 41. Beginning senior or junior high school
- \_\_\_\_\_ 42. Jail sentence of a parent for one year or more

APPENDIX F  
A SHORT SCALE FOR THE EVALUATION OF SOCIAL SUPPORT

(Cohen and Reiss, Note 6)

In this questionnaire you will be asked a variety of questions about yourself, your friends, your family, and your community.

1. Have you ever been married? (Check the correct answer)  
☐ Yes ☐ No (If no, skip next question)
2. Are you now married, separated, divorced, or widowed?  
☐ Married ☐ Separated ☐ Divorced ☐ Widowed
3. How many close friends do you have? (People that you feel at ease with, can talk to about personal matters, and can call on for help).  
☐ none ☐ 1 or 2 ☐ 3 to 5 ☐ 6 to 9 ☐ 10 or more
4. How many relatives do you have that you feel close to?  
☐ none ☐ 1 or 2 ☐ 3 to 5 ☐ 6 to 9 ☐ 10 or more
5. How many of these friends and relatives do you see at least once a month?  
☐ none ☐ 1 or 2 ☐ 3 to 5 ☐ 6 to 9 ☐ 10 or more
6. Do you belong to any of these kinds of groups?

	yes	no
A sports group (baseball, football, soccer)?	<input type="checkbox"/>	<input type="checkbox"/>
A church group?	<input type="checkbox"/>	<input type="checkbox"/>
School activity group (band, drama, cheerleaders)	<input type="checkbox"/>	<input type="checkbox"/>
Other activity group (4-H, girl or boy scouts)	<input type="checkbox"/>	<input type="checkbox"/>
7. How many of your friends are friends with each other?  
☐ none ☐ a few ☐ several ☐ most of them ☐ all of them



8. How often do you see, telephone, and write important friends and relatives ?

Select up to five relatives and friends that you do not live with who are most important to you. For each relative, fill in the person's relationship to you. For each friend, fill in the person's first name. Then fill in how often you are in contact. For example:

	<u>See</u>	<u>Telephone</u>	<u>Write</u>
(name or relationship)			
a. (name or relationship)			
b. (name or relationship)			
c. (name or relationship)			
d. (name or relationship)			
e. (name or relationship)			

On each of the following questions, first count all the people you know (including those with whom you live) on whom you can count for help of support in the manner described, and circle the appropriate number. If you have no support for a question, circle "0", but still rate your level of satisfaction.

9. How many people are there on whom you can really count to listen to you when you need to talk?

0      1      2      3      4      5      6      7      8      9

How satisfied?

very      fairly      a little      a little      fairly      very  
satisfied   satisfied   satisfied   dissatisfied   dissatisfied   dissatisfied

10. How many people are there whose lives you feel you are an important part?

0      1      2      3      4      5      6      7      8      9

How satisfied?

very      fairly      a little      a little      fairly      very  
satisfied   satisfied   satisfied   dissatisfied   dissatisfied   dissatisfied

11. How many people are there that you can really count on to be dependable when you need help?

0 1 2 3 4 5 6 7 8 9

How satisfied?

very fairly a little a little fairly very  
satisfied satisfied satisfied dissatisfied dissatisfied dissatisfied

12. How many people are there who will comfort you when you need it by holding you in their arms?

0 1 2 3 4 5 6 7 8 9

How satisfied?

very fairly a little a little fairly very  
satisfied satisfied satisfied dissatisfied dissatisfied dissatisfied

13. How many people are there on whom you can really count to tell you, in a thoughtful manner, when you need to improve in some way?

0 1 2 3 4 5 6 7 8 9

How satisfied?

very fairly a little a little fairly very  
satisfied satisfied satisfied dissatisfied dissatisfied dissatisfied

14. How many people are there who you feel truly care about you deeply?

0 1 2 3 4 5 6 7 8 9

How satisfied?

very fairly a little a little fairly very  
satisfied satisfied satisfied dissatisfied dissatisfied dissatisfied

15. How many people are there on whom you can really count to listen to you when you need to talk about medical or health concerns?

0 1 2 3 4 5 6 7 8 9

How satisfied?

very fairly a little a little fairly very  
satisfied satisfied satisfied dissatisfied dissatisfied dissatisfied

APPENDIX G  
PHYSICIANS' FORM FOR RATING LEVEL OF RESPONSE TO MEDICAL TREATMENT

Below are listed the names of patients who are participating in my doctoral research. For each patient, please rate the quality of response to medical treatment, using the following scale:

---

1	2	3	4	5
VERY POOR	POOR	GOOD	VERY GOOD	CANNOT
MUCH WORSE	WORSE	ABOUT AS	BETTER THAN	JUDGE AT
THAN	THAN	EXPECTED	EXPECTED	THIS TIME
EXPECTED	EXPECTED			

---

THIS IS NOT A RATING OF MEDICAL COMPLIANCE, OR OF PROGNOSIS. YOUR RATING SHOULD ONLY REFLECT THE RELATIVE QUALITY OF RESPONSE THE PATIENT HAS MADE TO MEDICAL INTERVENTION, GIVEN THE PATIENT'S DISEASE.

NAME	RATING				
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5

APPENDIX H  
LETTER TO RESEARCH FAMILIES

Dear \_\_\_\_\_,

Several weeks ago, I spoke with your family during an appointment at the Pediatric Clinic at Shands Teaching Hospital. At that time I invited you to participate in a study I am conducting on families with children with medical problems, and gave you some questionnaires.

I know that we all have many things to do, but I would appreciate it if you could take 15-20 minutes to complete these forms. If you have misplaced the questionnaires, and would like to participate in the study, please return the enclosed postcard. I will then send you a new packet of forms.

If you have any questions about the study, or a form, please feel free to call me.

Thank you for your help.

Sincerely,

John Reiss, M.A.  
Researcher

APPENDIX I  
INFORMED CONSENT FORM

University of Florida  
Shands Teaching Hospital  
Informed Consent Form

Participant's Name \_\_\_\_\_  
Hospital Number \_\_\_\_\_ Project Title \_\_\_\_\_  
Principle Investigator \_\_\_\_\_ Date \_\_\_\_\_

I agree to participate in the research as explained to me below:

The purpose of this study is to explore the psychosocial impact of chronic childhood illness on families and affected children, and to better understand the ways in which families and children cope with the problems they encounter. We hope to be able to use the information obtained in this study to better help families, like yours, adjust to the stresses of having a chronically ill family member.

If you agree to participate in this study, you will be asked to complete six questionnaires. These questionnaires will require you to think about your present family situation, recent events in your life, your attitudes toward medical care, and your relationships with friends and family. Your participation in this research will in no way affect the quality of the treatment you receive. The information obtained from these questionnaires will be kept confidential to the extent provided by law. Information will not be shared with your child's/your physician unless specifically requested.

At the conclusion of the study, you will be given an opportunity to meet with the investigator and discuss the findings of the study. If you wish, the results will be shared with your physician, so that specific suggestions can be made concerning the specific adjustment needs of your family.

The investigator who talks to you will be happy to answer any questions you may have, so that you can decide whether or not you wish to participate.

The above stated nature and purpose of this research, including any discomforts or risks, have been explained to me verbally by \_\_\_\_\_. Furthermore, it is agreed that the information gained from this investigation may be used for educational purposes which may include publication but that the information will not identify me or my child personally.

I have been fully informed of the above described procedure with its possible benefits and risks and have received a copy of this description. I have given permission for my and my child's participation in this study.

I understand that I am free to withdraw this consent and discontinue participation in this project at any time without its affecting my/my child's care.

Do you want information gained from these questionnaires shared with my child's physician: Yes \_\_\_\_\_ No \_\_\_\_\_

\_\_\_\_\_  
Signature of patient/subject/parent/guardian

\_\_\_\_\_  
Signature of child if 7 years or older

\_\_\_\_\_  
Witness to Signature

\_\_\_\_\_  
Date

APPENDIX J  
RESULTS OF ANOVA'S FOR GENDER AND RACE MAIN EFFECTS

Table 25. Means, Standard Deviations, and F Scores for ANOVA for Gender Main Effects (Across Disease and Race) for All Variables for Adolescents' Scores

Variable	Females (N=21)		Males (N=27)		F † Value	p Value
	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	22.42	4.46	19.74	4.84	1.81	.186
STRESS	186.38	116.98	187.85	130.35	.01	.936
APGAR	7.80	2.27	8.11	1.98	.51	.478
Dev APGAR	1.67	1.02	1.71	1.44	.45	.504
ADP	44.47	6.58	45.44	6.50	.45	.626
Dev ADP	5.09	4.04	4.51	4.61	1.16	.286
COH	57.42	10.43	59.18	9.09	.59	.448
Dev COH	7.44	7.18	6.85	5.87	.94	.337
FACES	1.17	.87	1.11	.78	1.19	.282

† N=48, df=1



Table 26. Means, Standard Deviations, and  $F$  Scores for ANOVA for Gender Main Effects (Across Disease and Race) for All Variables for Mothers' Scores

Variable	Females (N=18)		Males (N=24)		F † Value	p Value
	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	25.05	5.65	22.37	5.37	3.83	.058*
STRESS	167.05	110.37	183.00	118.65	.02	.887
APGAR	7.55	3.07	7.91	2.39	.35	.555
Dev APGAR	2.21	2.06	1.87	1.45	.28	.592
ADP	45.94	5.75	47.08	6.01	.10	.758
Dev ADP	5.09	4.04	4.58	3.80	.12	.731
COH	63.16	8.86	60.70	10.17	.58	.414
Dev COH	7.44	7.18	8.20	5.86	.34	.564
FACES	1.17	.87	1.28	.69	.01	.931
FFI	23.92(a)	7.48	23.50(b)	7.72	.00††	.944
FFIA	28.38(a)	9.33	28.64(b)	8.27	.08††	.775

† N=42, df=1      ††N=28, df=1

\*\* significant at  $p=.10$

(a) N=10      (b) N=18

Table 27. Means, Standard Deviations, and F Scores for ANOVA for Gender Main Effects (Across Disease and Race) for All Variables for Fathers' Scores

Variable	Females (N=10)		Males (N=11)		F † Value	p Value
	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	25.11	5.94	20.72	4.83	1.75	.207
STRESS	107.30	88.15	126.63	126.63	.06	.805
APGAR	7.00	3.19	7.72	2.53	.26	.615
Dev APGAR	2.40	1.99	2.19	1.12	.01	.928
ADP	47.30	10.75	44.72	3.31	.56	.465
Dev ADP	8.91	5.42	2.18	2.72	9.91	.006***
COH	65.80	11.13	62.36	8.07	1.02	.327
Dev COH	9.20	5.78	5.27	6.13	1.72	.209
FACES	1.55	.83	.69	.65	4.89	.042**
FFI	22.60(a)	7.19	25.55(b)	4.21	1.18††	.297
FFIA	27.40(a)	8.35	30.33(b)	5.02	.67††	.428

† N=21, df=1      †† N=16, df=1

\*\*\* significant at p=.01

\*\* significant at p=.05

(a) N=7      (b) N=9

Table 28. Means, Standard Deviations, and F Scores for ANOVA for Race Main Effects (Across Gender and Disease) for All Variables for Adolescents' Scores

Variable	Blacks (N=9)		Whites (N=39)		F † Value	p Value
	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	20.33	2.39	21.05	5.23	.14	.706
STRESS	124.66	73.27	201.64	128.68	3.64	.063*
APGAR	7.88	1.36	8.00	2.24	.07	.791
Dev APGAR	1.00	.85	1.85	1.23	5.19	.027**
ADP	44.66	6.55	45.10	6.55	.18	.678
Dev ADP	4.56	4.44	4.82	4.37	.33	.551
COH	59.66	6.85	58.12	10.22	.52	.473
Dev COH	5.39	3.99	7.51	6.83	2.00	.164
FACES	0.98	.67	1.17	.85	1.75	.193

† N=48, df=1

\* significant at p=.10

\*\* significant at p=.05

Table 29 Means, Standard Deviations, and F Scores for ANOVA for Race Main Effects (Across Gender and Disease) for All Variables for Mothers' Scores

Variable	Blacks (N=7)		Whites (N=34)		F † Value	p Value
	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	26.87	2.47	22.66	5.83	.91	.347
STRESS	195.62	157.71	171.58	103.82	.31	.578
APGAR	7.25	2.31	7.88	2.77	1.11	.299
Dev APGAR	1.81	1.38	2.06	1.81	.08	.776
ADP	46.75	6.51	46.55	5.80	.21	.648
Dev ADP	4.56	4.44	4.82	4.37	.46	.500
COH	64.50	5.15	61.11	10.33	.12	.734
Dev COH	5.39	3.99	7.51	6.83	2.15	.151
FACES	0.98	.67	1.17	.85	.48	.491
FFI	28.00(a)	3.46	23.16(b)	7.69	.17††	.688
FFIA	33.66(a)	4.04	27.87(b)	8.87	.21††	.650

† N=42, df=1

†† N=28, df=1

(a) N=5

(b) N=23

Table 30. Means, Standard Deviations, and F Scores for ANOVA for Race Main Effects (Across Gender and Disease) for All Variables for Fathers' Scores

Variable	Blacks (N=2)		Whites (N=19)		F † Value	p Value
	Mean	Standard Deviation	Mean	Standard Deviation		
ASSESS	26.06	4.24	22.33	5.79	.37	.552
STRESS	44.50	2.12	125.10	90.04	2.16	.162
APGAR	5.50	.70	7.57	2.89	1.45	.246
Dev APGAR	1.88	.70	2.33	1.68	.00	.967
ADP	43.00	4.24	46.26	7.98	1.00	.332
Dev ADP	3.00	4.17	5.63	5.50	1.08	.314
COH	57.50	.07	64.68	9.82	2.78	.116
Dev COH	6.50	.07	7.21	6.48	.01	.920
FACES	0.86	.18	1.12	.89	.14	.711
FFI	22.00	5.65	24.23(a)	6.16	.75††	.401
FFIA	28.00	4.24	28.88(a)	7.29	.49††	.496

† N=21, df=1

†† N=19, df=1

(a) N=17

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## BIOGRAPHICAL SKETCH

John Gilbert Reiss was born in New York City in 1949. At age three, John moved with his parents to Deerfield, Massachusetts. He graduated from Deerfield Academy, then headed to Oberlin, Ohio, to attend college. He received his A.B. (with high honors in psychology) from Oberlin College in 1972, and his M.A. from Wesleyan University the next year. After working several years as a counselor in a vocational rehabilitation center in Ohio, he spent a year travelling throughout the West and Southwest. He began his doctoral studies in 1977 at the University of Florida. In 1979 he did his internship at the University Counseling Center. Following this, he was appointed to a Counseling Associate position with the Center. In 1982, he was appointed to a pre-doctoral fellowship with Children's Developmental Services, Neonatology, Shands Teaching Hospital. In this position, John has been responsible for counseling services to parents of premature and low birthweight infants hospitalized in Shands Neonatal Intensive Care Unit.

John currently lives with his wife and infant daughter.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



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Professor of Counselor Education

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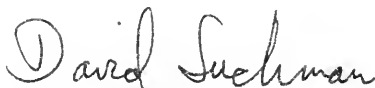
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This dissertation was submitted to the Graduate Faculty of the Department of Counselor Education in the College of Education and to the Graduate Council, and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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